

REDEFINING PARENTING: THE PROCESS OF RAISING  
ADOPTED CHILDREN WITH FETAL  
ALCOHOL EFFECTS  
(FAE)

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## Abstract

This thesis examines the experiences of parents who are raising their adopted children who have Fetal Alcohol Effects (FAE). Four married couples, and one single mother, who married after she had raised her sons participated in this study. All are white and middle or upper-middle class. Five adoptive mothers and one adoptive father were interviewed, while their spouses contributed to the study by reviewing the interview transcripts, and discussing issues raised within them. Eight children with diagnosed or suspected FAE are discussed. They are Cree or Saulteaux, and are between the ages of nine and 23. Through multiple in-depth interviews, and the demographic profile form, richly detailed information was recorded on these families' day-to-day lives: the children's school experiences, learning disabilities and behaviour problems, their strengths, their health and interactions with peers; parents' interactions with professionals, treatments and behaviour management strategies they sought or devised, their use of support groups and other forms of social support and encounters with the criminal justice and mental health systems.

Grounded theory methodology was used to analyse the data and a conceptual model was constructed to outline the process of *redefining parenting* which describes the practical and psychological tasks parents perform as the family evolves over time. A central role is taken by the mothers who become advocates for their children as they undertake a quest for the meaning of their children's behaviour, seek a diagnosis, and try to secure services for them. It was found that people with FAE are misunderstood and misdiagnosed because of their anomalous nature, which often leads to stigmatisation. This thesis attempts to dispel these misconceptions, document the parents' and children's struggles, and identify the types of services these families desperately need.

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## **List of Abbreviations**

<u>Abbreviation</u>	<u>Term</u>
SAPA	Saskatchewan Adoptive Parents Association
SADAC	Saskatchewan Alcohol and Drug Abuse Commission
IOM	Institute of Medicine
ARND	Alcohol Related Neurodevelopmental Disorder (See Appendix A)

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## Chapter One: Introduction

### 1.1 The Purpose of this Study

The aim of this study is to make a close examination of the experience of raising a child with fetal alcohol effects (FAE) as described by a specific group of adoptive parents. FAE is recognised by the medical community as a constellation of cognitive, psychological, and sometimes physical impairments caused by prenatal exposure to alcohol. While this condition is often described as a 'milder' form of fetal alcohol syndrome (FAS), longitudinal research has shown that individuals with FAE often face more difficulties than those people diagnosed with FAS (Connor and Streissguth, 1996). In comparing the differential diagnosis of FAS and FAE, Burgess and Streissguth (1992) state that, "FAE is not the less severe form of FAS; rather, a child with FAE does not have all of the physical abnormalities of FAS. The cognitive and behavioral characteristics of FAS and FAE are similar" (from Jenner, 1994). More recent research also concludes that

[t]he range of prenatal alcohol effects has been described as a continuum, with no effects at one end and full [sic] developed FAS at the other end. This view, however, can be misleading. Although patients with FAS have more physical deformities, such as heart malformations and facial anomalies the brain dysfunctions of people with FAE/ARND are often as severe as--if not worse than--brain dysfunctions in patients with FAS. (Connor and Streissguth, 1996: 170)

The term FAE encompasses a large and diverse group of people who may display some, but not necessarily all, of the following characteristics: learning disabilities, poor coordination, hyperactivity, poor judgment, trouble following rules and directions, and difficulties in managing both time and money (Streissguth et al., 1996).

Researchers have found that social and educational intervention with these children, applied as early as possible, can mitigate the potential negative effects of prenatal alcohol exposure: "Family experiences and expectations, cultural practices, schooling, and peer contact are all important: a good environment can foster development and buffer alcohol effects" (Olson, Burgess and Streissguth, 1992: 24). And, "[a] good social environment after birth does not seem to eliminate mental and perceptual problems for the children but can modify the outcome, especially in regard to interpersonal and social development (Aronson and Olegard, 1985: 144).

These research findings correspond to the experiences of parents reported in the literature (Kleinfeld and Wescott, 1993). Parents explained that the first step in helping their children was finding out that they had FAE. Once they have determined that their child has FAE through either an “official” or “formal” diagnosis by a physician, or through their own “informal” assessment, parents devote a tremendous amount of time and energy trying to remedy their children’s difficulties on two fronts: enhancing their child’s ability to adapt to the expectations of our culture (ie. peer group, school, employer); and providing information about FAE to key individuals who are in a position to modify the child’s environment to better accommodate his or her needs. Parents depend upon the services provided by professionals, particularly those in the medical and educational community. This rather intense and unusual enculturation process has a profound influence on the identities of these children and their parents. Parents must first educate themselves about FAE, and then take on the challenge of becoming advocates for their children. Some children may resent this directive (ie. authoritarian) style of parenting and may rebel or leave home.

## **1.2 The Anthropological Perspective**

At the heart of the complex problems associated with FAE is a fundamental social process which anthropologists call enculturation (Haviland, 1996: 122-123).<sup>1</sup>

Anthropological theory can provide a framework for analysing this multifaceted and dynamic social process. Since culture is based on shared knowledge, this information must be taught to new members of a society. This process of teaching individuals the values, rules and all the necessary skills and information necessary to survive in a particular culture is known as enculturation. This learning process begins at birth first with the mother, and then with other members of the household. Later, as the child ventures out into the community, peers, teachers, and other adults become agents of enculturation. People with FAE, however, have hidden disabilities which impede their capacity to understand and internalise their culture’s explicit and implicit rules of behaviour. On a personal level, this makes social interaction painfully difficult; on a societal level, they often end up in the justice system because they break laws, often unintentionally.

Because these children are different in fundamental ways from most other children, they must be raised differently. This different type of parenting must be invented by the parents through trial and error, until they find a framework for their action in the FAE diagnosis. Even then, they may be criticised by professionals and others who do not and cannot understand their experiences. An adoptive mother who testified at a parliamentary hearing on Fetal Alcohol Syndrome explains:

The next area that I think is really demanding for parents is the

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<sup>1</sup> This is similar to socialisation, and some anthropologists use the terms interchangeably.

need to always be clarifying our own values about what we are doing. It is easy to blame our children, it is easy to get upset and to get angry. We need to clarify our values about what parenting is like, and the kind of parenting I must do with my children is very different from what I was brought up to believe in....It also happens with professionals. A common reaction you get with professionals if you have an adolescent is that you just want to keep your child dependent on you; you don't want to encourage independence. On the contrary, I want to encourage independence, but I want it to be safe. So we get into incredibly convoluted discussions with professionals about what our motivations are. We end up getting psychoanalysed as much as our children do. So we really need to always be aware of what our motivations are and what our information is in order to help make us better parents. (Canada, 1992a: 33)

To complicate the issue, the families in this study are adoptive families, who have the difficult task of overcoming some of the hardships inflicted on these children in their obscure past. When they begin, they are pioneering a new path through uncharted territory. They have the additional responsibility of documenting their journey, and telling their story to others who will follow. These parents must revise misconceptions which are harmful for both themselves and their children. Another mother who testified in the parliamentary hearing sums up this misconception: "The myth that the adoptive family is the same as any family still lingers. The old myth that you could walk happily off into the sunset, that love would conquer all, doesn't work" (Canada, 1992b: 6).

An important element of the social context in which this story unfolds is the medical community which both undertakes the science which defines the nature of FAE, and provides many of the services which the individuals with this condition require. Social scientists have made critical analyses of the medical system as an institution, in order to lay bare the underlying assumptions upon which it is based, and the influence of these assumptions on the action of this system. Furthermore, these analyses elucidate the nature of the culture from which these values arise.

In her study of scientific research, Martin notes that when scientists produce new knowledge and it is disseminated throughout society, they always play an active role:

they translate, read write, mobilize, impose, convince [in their attempts to ] change an essentially passive world. [However],...[w]orking with a conviction that what scientists do can be seen as embedded within a complex cultural world with historical depth, anthropologists [using ethnographic research] have begun to reveal the intricacies of describing the work of scientists in the context of a world that is not assumed to be passive. (1994: 6-7)

According to Kleinman, a medical anthropologist,

[P]articular symptoms and disorders are marked with cultural salience in different epochs and societies. These special symptoms and illness categories bring particularly powerful cultural significance with them, so to speak, often of a stigmatizing kind [ bubonic plague, AIDS]. (Kleinman, 1995: 10)

That FAS/FAE is one of these conditions, is revealed in the passionate debates evoked regarding prevention efforts, and legal issues concerning the rights of the pregnant woman versus the rights of her child-to-be, which point out the ambivalent attitude towards alcohol in our culture. Furthermore,

The society-wide response to each problem also tells us much about the value structure of American society. We manage as medical problems the symptoms resulting from the social sources of distress and disease. We blame the victim in the ideology of personal life-style change. We avoid the hard, value-laden questions that underlie public health concern with cigarette smoking, exposure to carcinogens, promiscuous sexual practices, and what is euphemistically called unavoidable stress...Both cancer and heart disease intensify our awareness of the dangers of our times and of the man-made sources of much misery. But the governmental response is meant to obfuscate this vision of sickness as meaning something is wrong with the social order and to replace (medicalize) it with narrowly technical questions. (Kleinman, 1995: 21)

There is a recent, disturbing trend of portraying affected individuals as “born criminals” which is centred in a discourse which frames all behaviour (including criminality) as genetically based. A newspaper article with the headline, “Fetal alcohol syndrome linked to crime” begins,

As many as half the young offenders appearing in provincial court may be there because their mothers drank during pregnancy...The youths are born with fetal alcohol syndrome (FAS), and they move undiagnosed through the criminal justice system. Given the nature of their affliction, they often reoffend when released. (Zakreski, 1998: A1)

The article goes on to argue that these individuals are often not responsible for their actions, and that the justice system must adapt to meet their needs. However, the opening lines portray these young people as making the leap from birth to the justice system, and implies that they should be diagnosed when entering this system. The actual figure reported by Fast et al. is 23.3 percent of young offenders who were remanded for

forensic psychiatric or psychological assessments in Youth Court Services in Burnaby B.C. over a one year period. These young people, then, had severe behavioural or psychological problems (Conry, 1999). An article in the Globe and Mail (Roberts, 1998, A1, A6) is more damaging and inaccurate. It describes the case of the murder of Helen Montgomery in North Battleford, SK by two “juvenile offenders” who had been in her custody for only 24 hours. The crime sparked a petition signed by 25,000 people to toughen the young offenders act. It states that “...the girl...suffers from a neurological disorder called fetal alcohol syndrome (FAS), an often undiagnosed form of retardation that can impair the ability to distinguish right from wrong...[She is] someone who does not have a conscience.” It says fetal alcohol effects is a less severe condition than FAS, and that “people with extreme forms of FAS show a marked inability to form moral judgments” (Ibid.).

A child-care worker is quoted,

‘So much of what goes on in school is beyond them. It leads to total frustration and then criminal activity.’ The jump from learning disability to crime is not neatly documented. But experts say the growing number of FAS cases could have tremendous implications for the way in which the criminal-justice system handles youngsters in custody (Ibid.: A6).

Finally, Ken Murdoch, program director for Winnipeg Child and Family Services says, “I’ve seen pictures of this and it’s gruesome. It’s literally holes in the brain.(Ibid.)”

There are several common misconceptions about FAS/FAE presented in the preceding article excerpts. I will address them briefly here, and attempt to dispel such myths throughout this thesis by reviewing the latest findings by experts in the field, and presenting detailed stories about the experiences of children, teenagers, and young adults with FAE and their families.

According to Habbick et al. (1996) the rate of FAS in Saskatchewan is not growing but has remained relatively steady over the past twenty years. Next, as discussed earlier, FAE is not less severe than FAS. An “extreme form” of FAS has not been described in the literature, although Coles et al. (1997) speculate that children with FAS who exhibit hyperactivity may be more severely affected than those who do not. Furthermore, individuals with FAE are just as disabled in their ability to form moral judgments. There is no natural progression from learning disability to criminality. Many children with FAE drop out, or are expelled from schools which are unwilling or unable to meet their needs. They often suffer from depression, have Attention Deficit Disorder, and are at high risk for addiction problems. There are few places in residential schools, treatment centres, or group homes to accommodate these young people. Consequently, many end up on the streets, and, with little education and no employment skills, turn to crime to support themselves. Finally, most of the neurological damage, especially in



those with FAE, is the result of subtle changes to the structure and physiology of the brain which takes place at a microscopic level. Gruesome holes in the brain, however, are not necessary to cause profound learning and behavioural dysfunction. Mothers, as members of society and consumers of images and ideas presented in the popular media are not immune from these misconceptions. Josie, who is only recently getting “caught up” on the latest FAS/FAE research describes her impression of her son.

Josie:

I used to think Mark had holes in his head, even before I saw any of those pictures of damaged children’s brains. He seemed to have big holes in his head. He had some real strengths and huge deficits. He was impetuous. I thought he was like a sociopath, had no intrinsic sense of right and wrong, good and bad.

While FAE is not genetic, or heritable<sup>2</sup>, researchers have found organic correlates in the brain, present at birth, which they link with specific gaps in cognitive and perceptual abilities. This brain damage affects such basic human attributes as symbolic communication and empathy. The discovery of a large number of individuals with FAS/FAE in the prison population (Zakreski, 1998: A1-A2) has encouraged a neglect of environmental factors in both a person’s development, and the social and economic factors which shape society in favour of targeting their biology as the causal agent for their criminal behavior. For instance, many people in this province with FAS/FAE are Native (Habbick, 1996), and Native people make up a large proportion of the incarcerated population. According to recent statistics, while Native Canadians make up two percent of the Canadian population, they represent ten percent of the incarcerated population. (Bayda, 1995). The situation is particularly disturbing in Saskatchewan, where 72 percent of the prison population is Native, whereas they comprise 15 percent of the total population (Ibid.). Were these individuals incarcerated because of inequities in the justice system, because they have FAS/FAE, because they have no financial resources and are living in the streets, or due to a combination of these factors? While these inequities are the object of inquiry and legal reform, which seeks to remedy systemic racism, this issue fades under the shadow of the the medical (or biological) discourse.

This is a dangerous resurgence of biological determinism which Martin (1994) chronicles for visible minorities and people with AIDS, and Edgerton (1967) outlines for the mentally retarded. As Native people with cognitive disabilities, the young people in this study inhabit a perilous region. Those who are still children are even more vulnerable.

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<sup>2</sup> Although, since the disposition to become alcoholic, or substance-dependent may have a genetic factor, people with FAS/FAE are a very high risk group for developing addictions (Streissguth, Moon-Jordan and Clarren, 1995).

This thesis cannot fully explore these issues, but some discussion of them is provided as a background: they are the social and ideological matrix of their parents' struggles, and help explain the intensity of these efforts. In more senses than one, their children's lives are at stake.

### **1.3 Methodology**

Earlier studies on FAS and FAE have focused primarily on examining the physiological mechanisms which cause damage to the fetus, documenting the specific nature of the impairments, and studying the epidemiology of FAS. I discovered only two studies (Stade, 1995 and Raymond, 1997) which focused on the experiences and opinions of parents of children with FAS/FAE. Since the voices of parents are under-represented in the "official" or "legitimate" literature of academic journals and research reports (including theses), the goal for this project was to focus on the views of the participants rather than those of the medical community or other professionals. The six participants, five adoptive mothers and one adoptive father, are white and middle or upper middle-class, and are all in their forties and fifties. All have some post-secondary education, from vocational college diplomas to doctoral degrees. Eight children, all of Cree or Saulteaux origin, with diagnosed or probable FAE are included in the study.

While this research is not designed to establish generalisations about all those who are parenting children with FAE, a review of the limited literature written by other adoptive and biological parents of children with FAE and FAS (Dorris, 1989 and 1994; Davis, 1994; Kleinfeld and Wescott, eds. 1993; and McCreight, 1997) and research on these parents (Stade, 1995, and Raymond, 1997) shows that they share many common experiences.

Using grounded theory as the methodological framework, I intended to document both the similarities and differences among the families, and compare these with findings of previous researchers, and the experiences of parents discussed in the above works. The primary method of data collection was multiple, semi-structured in-depth interviews with the adoptive parents of children with FAE. The participants provided richly detailed answers to the interview questions, discussing many issues which they identified as most relevant to their day-to-day lives.

A demographic profile was also constructed. The demographic profile is a standardised form which the parents completed, to document basic demographic information about the family, and the children's health status and school history. The demographic profile is discussed in detail in Chapter Three, and appears in Appendix H. The research design, data collection and analysis are also detailed in Chapter Three. It was important to collect medical and educational data to compare the results with previous studies since these are the types of information most often documented in such research. Likewise, I wanted to provide similar information from this study for future researchers.

It was also important to ascertain characteristics of the children which would help me to compare them with the profiles given for the FAS and FAE classifications, and the new categories provided by the proposed diagnostic criteria (Stratton, Howe, and Battaglia, eds., 1996). The medical and educational literature regarding FAS/FAE will be reviewed at the beginning of Chapter Two.

While grounded theory models must be grounded in the data, and should not conform to a preconceived theoretical construct (Strauss and Corbin, 1990), previously established concepts and theories which are relevant to the emerging model may be incorporated into that model. In this case, concepts have been adapted from: Mary Douglas (1995), regarding how our society views anomalous individuals; Robert Edgerton et al. (1976 and 1984) and Edgerton (1967, 1984a and 1984b) on anthropological studies of the mildly mentally retarded; and Emily Martin's (1994) more recent work on the meaning of health and stigma in the 1990s; Arthur Frank (1995), and Arthur Kleinman (1995) regarding illness narratives; and Fulcher (1992) about the way we discuss disability.

#### **1.4 The Participants: Characteristics**

The following is a summary of the information about the children and parents contained in the demographic profile which is discussed in detail in Chapter Three. A profile of each family is presented below under the heading "Family Histories." Five families are included in this study, consisting of married couples with two or more children. Not all of these children are currently living at home. Susan and Carl have two biological children who are young adults attending university, and a younger adopted son. The other four couples have no biological children. Each couple adopted two children close in age. Paula, who is now married to Clive, was a single mother when she was raising her sons. All the parents are white, second and third generation Canadians, of Eastern European, Scandinavian, and British origin, and are all in their forties and fifties. All have some post-secondary education, from vocational college diplomas to doctoral degrees. Their socioeconomic status is middle or upper middle class.

The children, who are all either of Cree or Saulteaux origin, left their birth families as infants or toddlers and all spent some time in foster care. They were between the ages of one and three years when they were adopted by their new parents. At the time of the interviews they were between the ages of nine and 23.

Although this study focuses on the parents' experiences, previous studies (Stade, 1995; Raymond, 1997) reveal that parents of children with FAS and FAE spend a great deal of time and energy trying to understand their children's learning or behavioural problems, and remediating physical problems related to their birth defects. Furthermore, both understanding and access to services were closely tied to receiving a diagnosis for the child. In order to explore these issues, it was important to include questions about the

children's medical and school histories.

#### **1.4.1 The Children's Health**

Their medical histories reveal that the children did not suffer from serious illnesses, but many had to overcome early developmental problems. The following list is not comprehensive, but makes reference to those health problems commonly found in children diagnosed with FAS (Streissguth et al., 1996; Habbick et al, 1996). These are discussed with reference to each child in the family profiles below, and elaborated and contextualised in the narratives which appear throughout this thesis.

Three of the children were small at birth, and one of these also had a small head circumference. The eldest of these is now of average height and weight, while the younger two are still small in stature. One child has severe speech and language problems and another has a cleft lip and palate. These problems were repaired surgically, and after speech therapy his language is now normal. Three of the children had frequent ear infections, which led to hearing loss in two of them. Two children have serious vision problems. One child is hypersensitive to touch, and has coordination problems and gait and musculoskeletal difficulties which were not resolved through either time or therapy. Four of the children were put on the drug Ritalin at some point in their lives. Two of them were formally diagnosed with Attention Deficit Disorder (ADD), and their mothers report that the Ritalin was very helpful to them. In the other two cases, the side effects were severe, and the drug was discontinued. All of the children have some behavioural or social adjustment problems, although these vary greatly in severity. The three young adults all have problems with substance abuse.

#### **1.4.2 School Experiences**

While the school experience of each child is unique, in the majority of cases these experiences were reported as generally negative, with the positive aspects being the exception. The two people who were identified at an early age as needing special educational services had a much smoother school career. All the children currently aged nine through twelve were in regular classrooms with modified programs, and some had help from a teaching aide. The two eldest in this study had no extra help in school although they had many difficulties. Their parents sought help such as tutoring and counselling, but both dropped out of school at an early age.

#### **1.5 The Family Histories**

Below are brief sketches of each family to introduce the main characters in each of their stories, as well as the main events covered over the course of the interviews. Information about the biological families is also included in the family profiles to the extent that it was available. It is important to include information about the children's

biological families because they remain present throughout these children's lives. While they are usually in the background, specific events bring them into sharp focus in foreground.

### **1.5.1 Josie's Family**

Josie and her husband, Bob, are both in their early fifties, and professors in health related fields. They have two adopted sons who are of Cree ancestry: Mark and his older brother Ian are both in their mid-twenties. Mark is alcohol-affected but his brother, Ian, is not. At the beginning of this study, both boys were living away from home. Mark was living with his biological family. Several months later, they both moved to Ian's home reserve. Mark is currently living with his girlfriend's extended family who are band members of this same reserve.

Ian was adopted as an infant, and his mother recalled that she bonded with him easily and had no particular difficulties during his early childhood. Mark, on the other hand, was adopted at three years of age. Josie did not have detailed information about the birth family but knew that he had been apprehended because his mother was abusing alcohol and the family could not care for him. There had been physical abuse, which caused Mark to have night terrors for many years. Mark spent 18 months in a foster home before being adopted by Josie and Bob. At the time of the adoption he was "different" from other children his age. Josie remembers that he was indiscriminately friendly, and that he forgot his previous toilet training, remaining in diapers until the age of five. His mother took several years to establish strong emotional bonds with him.

Josie and Bob moved to several locations around the world when the boys were young since they worked for international development agencies. Mark's development during childhood was relatively normal, but he did require extra help to keep up with his peers in school. He was diagnosed with ADD and put on Ritalin at the age of 11, but by this time his mother had heard of FAS and thought that her son might be affected. The more she learned, the more confident she became in her conclusion that Mark had FAE. He has never been officially diagnosed.

Mark became quite defiant as a teenager. Both he and Ian were involved in scrapes with the law for minor theft. Mark became increasingly frustrated with school in high school and began skipping classes. When Mark was sixteen he started drinking and quickly became an alcoholic. He went into residential treatment, and also spent some time in youth detention facilities. His parents became members of a SADAC support group which Josie says is the only thing that held them together during this troubled time.

In the last few years, Mark has settled down considerably, and has developed a real interest in Native spirituality. Josie facilitated Mark's search for his biological family at his request when he was 19. He chose to go and live with them in another city. Last year, however, Mark moved to his girlfriend's reserve, where Ian is also living with his

biological family. Josie describes Mark's girlfriend as a very nice girl with a nice family. Mark and his brother are both still in contact with their adoptive parents. Although Mark continues to struggle with his alcohol addiction Josie is hopeful for his future.

### **1.5.2 Eva's Family**

Eva is in her forties and her husband Larry is in his fifties. Eva is self employed and Larry is a skilled tradesman. Their two adopted Sauteaux sons, Cameron and Tim, are preteens. Cameron, the oldest, was adopted as an infant, and bonded easily with his adoptive mother. He lived in one foster home before being adopted. He was put into care because he had a cleft lip and palate and his mother felt she could not care for him. These problems were corrected by several surgeries. Although he is very slim, he has no health problems. When their youngest son Tim was adopted as a toddler he was severely language delayed and also had trouble walking. He had been placed in care at three months of age because he was extremely neglected, and had lived in two foster homes before the adoption. Tim has hearing and speech problems, and is the only child in this study who is classified by the education system as "mentally challenged" because he has an IQ of 70. There was "some mention" of alcohol being a problem for both biological families in Social Services reports at the time of the adoptions. Eva has not maintained contact with either family, but says that she would support her sons if they decide to search for their biological parents when they are older.

Tim was diagnosed with FAE as a preschooler. Cameron was diagnosed recently, in the summer of 1997 while the interviews were in progress. Both boys are in regular classrooms at school. Cameron is beginning to find academics more difficult as he gets older, but has passed all his subjects. He has begun to have some minor problems with the law, including shoplifting, but his parents have put supports in place to try to remedy this situation. Tim has some of his school subjects, such as math, modified and is helped by a half-time aide. The boys are involved in many activities outside of school. They go to summer camp every year, Tim has taken dance and voice lessons, and Cameron has studied hoop dancing. They both are very physically active and enjoy sports.

### **1.5.3 Debbie's Family**

Debbie and her husband, John, are both in their forties. Debbie has a background in health care, and now runs her own business. John is a teacher. This couple has two adopted daughters who are biological sisters; Kate and Becky are preteens. They are Cree, and treaty status. Debbie and John have pieced together a considerable amount of information about their daughters' biological family from both their Social Services records and the girls' older sister Hannah.

Their biological mother is now in her mid-thirties. Since her oldest child (who, as far as they know, is in prison) is in his twenties, she may have been as young as 11 or 12

when she first became pregnant. Debbie thinks she may be alcohol affected, since the grandmother was also drinking. Apart from this oldest son (there are no official records of him), Kate and Becky have five siblings, three older sisters, and a younger brother and sister. There was no mention of the father, or any other male living in the household before the girls were apprehended. The grandmother helped raise the children, and the older sisters also did some of the caregiving. When the grandmother died in a fire, around the time Becky was born, their mother was unable to cope. Debbie thinks that this is when Kate suffered the majority of her neglect, in the year before the children were apprehended.

Their three older sisters are now in their teens. Hannah is the oldest, and has kept in touch with Debbie and John. She grew up in a foster home and is now living with her boyfriend and his family. The second oldest was placed in foster care but kept running away from her foster homes. She spent two years in a centre for children with emotional problems and seemed to thrive on the structure and supervision they provided. She had to be released, and is now living in another city with her younger sister and is using drugs and alcohol. The younger girl was adopted by a Native family, but the adoption was disrupted because of her behaviour problems. The two youngest children were living with their biological mother until recently but have now been apprehended. Their mother, at the time of the interviews, was pregnant with her ninth child.

Kate was adopted as a preschooler. She was neglected and abused in her biological home, and, according to John and Debbie, received adequate care but little physical contact in her foster home. Her preschool teachers reported that “something was not quite right” with her, but she did not receive counselling until she was eight for presumed “attachment disorder.” Kate still has severe behaviour problems. She is very aggressive toward her younger sister and if not carefully managed, gets into fights with the other children at school. Kate can read fluently, but has problems with such tasks as organising her work, and is especially weak in mathematics. She is in a regular classroom with a highly modified curriculum, and has two half-hour sessions a week with the resource teacher. Kate enjoys sports and music, and working with her dad in his shop.

Becky is very popular in school, and has a close circle of friends. She began to have difficulties with academics in grade three, but was overlooked by teachers because of her quiet, cooperative nature. She has developed ingenious methods for covering up her inability to perform, and as her mother put it “would rather die than ask for help.” Becky is in a regular classroom with a modified program and has two half-hour sessions a week with the resource teacher. She is very artistic, enjoys socialising with her friends, sports, and dance.

#### **1.5.4 Paula’s Family**

Paula was a single mother while raising her sons. She is an instructor at the

university. Paula was recently married to Clive. She has two sons; Jason, who is in his early twenties, and Brad, who is in his late teens.<sup>3</sup> She adopted Jason when he was a preschooler. Jason's biological mother was heavily abusing alcohol and drugs and was severely disabled from the complications of alcoholism by the time Jason was placed for adoption. She now requires constant care. Jason has a twin sister who has spina bifida, heart defects, kidney problems, and is mildly retarded. Both Jason and Paula have met with her, and they are in contact with his grandmother and his older sister. An older brother died of kidney failure while still a child. Paula had been told by Social Services that Jason's twin had Down syndrome but she is quite sure she did not, that she had FAS.

Apart from being somewhat stubborn when he was young, and being aggressive with his younger brother, Jason had a normal childhood. In fact, until he was in grade seven, he excelled in school, often being at the top of his class. In junior high he started having difficulties academically, especially in mathematics. At this time he started getting in trouble at school and at home, rebelling against the rules, stealing small items, and becoming increasingly abusive toward his brother and the children at school. He was charged and sent to mediation sessions after he took his grandmother's car without permission and crashed it into the garage. Jason also began abusing alcohol and drugs. After this incident, he spent short periods of time at home, was in and out of youth detention, or lived on the streets. Jason came to identify strongly with a group of street youth who were involved in increasingly serious crimes. After committing many break and enters, they were finally caught following a gun shop robbery. Jason was arrested and received a lengthy sentence at a youth detention centre. At the time of the interviews he was in jail. He was not diagnosed with FAE until recently, as an adult in the correctional centre. Paula described Jason as very articulate, with excellent skills in English. He enjoys art, especially drawing, and played the trumpet in his high school band. While incarcerated he earned his G.E.D. and took a university course in Native Studies.

Brad was a toddler when he was adopted, however his developmental level was more like that of a young infant. He had spent his infancy in a foster home where he was cherished by his "foster grandma." Paula has stayed in touch with her and they visited frequently when he was first adopted. Brad still keeps in touch with her and recently went to see her. He had severe food allergies as a young child, and had repeated ear infections which left him with hearing problems. He still suffers from chronic bronchitis, and has poor vision, and hip dysplasia. Brad's biological mother is now sober, has left her alcoholic husband and is remarried. She has seven children from this second marriage, and apart from a tendency to respiratory problems, these children are healthy. They keep

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<sup>3</sup> Jason died of an accidental drug overdose in June of 1998, only a week after being released from the correctional centre, and approximately one year after the interviews with Paula were completed.



in touch with Paula, have made occasional visits, and, when Brad was younger, Paula always gave the children Christmas presents in Brad's name. Brad's three older biological brothers have been involved in increasingly serious crimes since their early teens, have lived in the streets, and been in and out of jail. His older sister, who has addiction problems, has three children. Her oldest daughter is in foster care, and her youngest two sons live with her. Paula says that the youngest boy shows all the signs of FAS. Brad sometimes lives with this sister.

Once Brad had his learning disabilities and perceptual problems evaluated in grade three, he did well in school in a modified program. He was always under the strong influence of Jason, and also his biological brothers who drew him into criminal activities and, eventually, life on the street. He has been abusing drugs and alcohol since his mid teens, and this problem eventually led to his leaving school. Brad has received counselling and taken part in detox programs. At the time of the interviews he was living with his girlfriend and their infant son. While he has not been formally diagnosed, his mother strongly suspects that he has FAE.

#### **1.5.5 Susan's Family**

Susan and her husband, Carl, both run a farm and have outside employment. Both Susan and Carl are educators. Susan is in her forties, and Carl in his early fifties. Their biological son and daughter are young adults. Kelly has just graduated from university, and Scott is in his first year. Their adopted son, James, who is Cree and treaty status is now ten years old. He was adopted as a preschooler, and lived in two or three foster homes before that. They are a Christian family, whose faith plays an important part in their everyday lives.

James was language delayed when he was adopted and was not toilet trained. Social Services provided the information that his birth mother had been abusing alcohol during her pregnancy and was intoxicated when James was born. All seven of her children were put into care when James was one-and-a-half. Three of these siblings were adopted by a family who live in a nearby community, and they have visited James a few times. Two of them have many of the features of FAS, according to Susan. Susan and her husband were also informed that James was both physically and sexually abused. His mother says that James' last foster home (he was in two or three placements before he was adopted) had six children (one who was severely disabled) being cared for by a single mother, who only had time for basic care. She had no time to toilet train him or work on his language problems. He was a very active child and turned the house and family upside down when he arrived in his adoptive home. After a difficult few months, he became an integral part of the family, with Scott and Kelly willingly helping to raise him.

James has emotional and behavioural problems, and has been seeing a counsellor since the age of four. He is large for his age, very aggressive, with a quick temper. He

was diagnosed with Attention Deficit Hyperactivity Disorder and put on Ritalin by a child psychiatrist when he was in grade two. His mother, however, was quite sure he had FAS and pushed for a diagnosis. In the following year the psychiatrist diagnosed FAE, and later found that James had dyslexia. This psychiatrist has suggested to Susan that James may later develop schizophrenia. James is in a regular classroom with a part-time aide. He belongs to the Boy Scouts, and enjoys sports and creating things in his father's workshop. James is very artistic, and has a special talent for drawing.

## **1.6 Organization of the Thesis**

This thesis will examine previous research into fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE) through the lens of the personal experiences of parents who are raising children with FAE. Since these are all non-Native adoptive parents who have adopted Native children, the history of adoption in this province and research related to the outcomes of transracial adoption is presented. FAS/FAE is the only cause of birth defects which can be prevented by mothers-to-be abstaining from alcohol; consequently, a great deal of research has been devoted to prevention, but efforts such as public education are reported to have had little real effect (Habbick et al., 1996). Some issues which provide the broad backdrop to the root causes of alcoholism will be addressed briefly in the literature review, because they have had a lasting effect on the children. A full development of the nature of the prevention problem will not be carried out here since it is now of little importance to the families, and is worthy of a thesis in itself.

The literature review will also include discussions of the mechanisms by which alcohol causes damage to the developing fetus, and reasons for the variability in outcome of exposed infants. It will also cover points of debate in the epidemiology and diagnosis of FAS/FAE. The most recent research investigating the learning and behavioural problems of affected individuals, and interventions to address these problems will be presented. Finally, other studies of parents with disabled children, non-technical or "lay" literature on FAS (including parent newsletters) and literature relating to both grounded theory and narrative analysis will be introduced, and revisited in the theoretical discussion in the final chapter which discusses the findings and implications.

Chapter Three will present a detailed description of the research methods used in this study to collect and analyse the data. The primary data for this study are the narratives which were constructed from the transcribed interviews. A summary of the explanatory model which resulted from the analysis is also contained in Chapter Three. The greater part of this thesis is composed of four interconnected chapters which present the results of the analysis. Taken together they constitute the process of family formation which I have labelled *Redefining Parenting*. The major stages of this model are explained in Chapters Four through Seven: *Becoming a Family, Living day-to-day I Creating the Local*

*Community, Living day-to-day II: Becoming Advocates, and Falling Apart and Reconnecting.*

### **1.7 Summary**

This chapter has presented an overview of the thesis, introduced the main actors in this drama, who are the families who so generously agreed to participate in this study, and presented a synopsis of the main events in the stories which the parents told to me. Chapter Two presents a review of the literature.

## **Chapter Two: Literature Review**

### **2.1 Introduction**

This chapter reviews the literature related to FAS and FAE which is relevant to this thesis. It also surveys the anthropological and sociological literature which is necessary for the development of the theoretical model which is described in Chapters Four through Seven and elaborated in Chapter Eight.

An understanding of the medical background of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), and the consequences for affected individuals requires a broad reading across many disciplines. Medical journals contain research about the prenatal effects of alcohol on the fetus and resulting birth defects. Psychology journals document literature on central nervous system (CNS) dysfunction as well as the psychological and behavioural characteristics of individuals with FAS and FAE. Journals from the field of alcohol studies discuss the issue of alcoholism as well as research devoted to the effects of alcohol on the body. Special education journals report on school programming for students with FAS or FAE. Informative articles can also be found in journals related to social work, family studies and nursing. While this chapter cannot do justice to this vast and quickly growing literature, it includes information from all those disciplines which I used in conducting the research for this thesis.

A recent volume (Stratton, Howe, and Battaglia, eds., 1996) brings much of this information together, takes stock of current knowledge and makes recommendations for future research. Conference proceedings provide a valuable multidisciplinary approach to the subject of FAS/FAE.

I used quotes from adoptive parents who testified at the Commons Subcommittee Hearings on FAS (Canada 1992a and 1992b), books and articles written by other parents (Dorris, 1989 and 1994; Davis, 1994; Kleinfeld and Wescott, eds., 1993; and McCreight, 1997), information from community consultations and needs assessments (Manitoba Medical Association, 1993; Tournier, 1994) and quotes from the studies by Stade (1995) and Raymond (1997).

This chapter covers the following topics which are interwoven with the views of parents and families drawn from first-hand accounts written by parents of children with FAS/FAE and research studies of families: 1) the medical definitions of FAS/FAE; 2) obtaining a diagnosis; 3) the characteristics of individuals with FAS/FAE; 4) treatment strategies and educational intervention; 5) research and prevention issues; 6) studies of chronic illness and disability; and 7) stigma, illness narratives, and social support.

## **2.2 Diagnostic Criteria of FAS/FAE**

An understanding of the medical dimension of FAS/FAE is a necessary foundation for further discussions since FAS and FAE were first identified by the medical community, a diagnosis can only be made by a medical specialist, and affected individuals often have some medical problems. Furthermore, parents value the contribution that medical and other researchers are making in the prevention and treatment of FAS/FAE. However, this researcher takes the perspective that the parents are the experts on their own children, and their narratives take a central role in this thesis.

FAE is best understood in relation to Fetal Alcohol Syndrome: FAS. FAS is the full expression of a spectrum of effects (Ernhart, 1991) which are caused by the exposure of a developing fetus to alcohol. Alcohol is a teratogenic drug which can cause a variety of physical and intellectual birth defects to the developing infant in the prenatal period (Stratton, Howe, and Battaglia, eds., et al, 1996).

For a diagnosis of Fetal Alcohol Syndrome to be made, there must be a history of maternal drinking with abnormalities in each of the three areas listed below. The term “fetal alcohol syndrome” was first used in 1973 to describe a small group of infants with a specific pattern of birth defects, low birth weight and central nervous system dysfunction, who were born to women who were chronic alcoholics (Jones and Smith, 1973). From these characteristics, and those discovered in later studies, diagnostic criteria were determined. These criteria have been refined by Rosett (1980), Clarren and Smith, (1978) and Sokol and Clarren (1989).

The current diagnostic criteria for FAS are as follows:

- 1) a clear history of prenatal alcohol exposure; 2) dysmorphic features (primarily observed in the face, such as short palpebral fissures, a pattern of flattened midface, smooth and/or long philtrum, and thin upper lip; 3) growth retardation for height and/or weight below the 10th percentile; and 4) CNS dysfunction (as manifested by microcephaly, developmental delay, hyperactivity, attention and/or memory deficits, learning difficulties, intellectual deficits, motor problems, neurologic signs, and/or seizures). (Streissguth et al., 1996)

There is also an increased incidence of physical problems including cleft lip and palate, kidney and heart defects and malformation of the joints (Stratton, Howe, and Battaglia, eds., 1996). If there are abnormalities in only one or two of the categories listed above, the term ‘Alcohol-Related Birth Defects’ (ARBD) or fetal alcohol effects (FAE) is commonly used (Ernhart, 1991). FAE is not currently a medical diagnosis (Streissguth, personal communication July 1998). This terminology is currently under review, and the most recent proposed typology is presented in Appendix A. Since the parents I interviewed used the term “fetal alcohol effects” or “FAE” to describe their children, I use

this term throughout this thesis.<sup>1</sup>

FAS is described as a 'preventable tragedy' in the literature since it will not occur if a pregnant woman does not drink alcohol, and has been identified as the leading known cause of intellectual disability both in the United States (Abel and Sokol, 1991) and worldwide (Loock, 1994), surpassing Down syndrome and spina bifida.<sup>2</sup>

### 2.2.1 The FAE "Diagnosis"

People with FAE have fewer physical problems than those with FAS and are often of normal height and weight for their age. Furthermore,

The "diagnosis" of fetal alcohol effects or ARBD [Alcohol Related Birth Defects: physical birth defects] and ARND [Alcohol Related Neurodevelopmental Disorder: behavioral and cognitive problems] and the estimation of their incidence are more difficult than that of FAS.<sup>3</sup> The specificity of the FAS diagnosis for alcohol makes it clinically useful and scientifically meaningful. ARBD and ARND, however, are not syndromes in the classic sense, but the presentation of FAS signs individually associated with, but not specific to, prenatal alcohol exposure. They can be "lower dose" manifestations of FAS, but they can also reflect the timing of exposure, dose of teratogen, genetic factors in mother or fetus affecting metabolism or susceptibility, and interactions with other environmental exposures, all known to modify outcome to potentially teratogenic exposures. (Sampson et al., 1997)

It must be emphasised that each person with FAS or FAE is a unique individual, whose personality and personal experience are mediated by specific physical and/or neuropsychological changes caused by complex interactions among alcohol, the mother, and the fetus (Stratton, Howe, and Battaglia, eds., 1996).

FAS is a medical diagnosis (Streissguth, personal communication, 1998) which requires both a physical examination, and psychological testing. A geneticist or dysmorphologist (Stratton, Howe and Battaglia, 1996) is the most qualified person to do the physical exam because many genetic disorders share some similarities with FAS/FAE. While, "[c]urrently, there are no standardized psychological or behavioral tools, that can be used to make this diagnosis, ... such testing can be used to corroborate medical opinion." (Burgess and Streissguth, 1992: 24, from Jenner, 1994).

Jenner, in her research on the educational aspects of FAS/FAE notes that

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<sup>1</sup> When I wish to include the full spectrum of alcohol related effects, I use "FAS/FAE" or "FAS and FAE" since these are the terms used by the participants, and in most of the literature here reviewed.

<sup>2</sup> There are 350 known causes of mental retardation, and many unknown causes. (Westman, 1990)

<sup>3</sup> See Appendix A.

a diagnosis made at birth is based primarily on specific facial features and growth deficiencies. In preschool children, functional deficits and behavioral disorders become more prominent. If a child is suspected of having FAS, they should be monitored closely through their infancy and early childhood. Therefore, “early childhood educators are in a prime position to notice functional deficits and behavioural disorders” (p. 12).

As discussed in Chapter One, it is erroneous to call FAE a “milder” form of FAS since the behavioural and cognitive difficulties are just as disabling as those of FAS.

The diagnosis is a complex one. The following description provides some possible links between structural damage to the brain, and neurological and behavioural effects which can be observed by a diagnostician:

No single expression of structural or functional brain damage is universal or pathognomic when patients with the FAS face and a clear history of alcohol exposure are reviewed. Evidence of abnormality in this field may be structural, neurologic or functional. Microcephaly was emphasized as a necessary marker for structural damage in early reports, but many, if not most, clinicians who diagnose a lot of children with FAS do not regard this as a necessary finding now. Only 16 autopsies of humans with FAS have been published; these suggest a diversity of lesions in multiple sites. CT and MRI images of the brain have been reported to display mild changes in ventricular size, disruptions in structure such as hypoplasia or agenesis of the corpus callosum, and decreased cerebellar size. Neurologic evidence for brain damage may include seizures, abnormalities in muscle tone, tremors, abnormalities in coordination, neurosensory hearing loss, or visual anomalies stemming from small optic globes. (Stratton, Howe, and Battaglia, eds., 1996: 72-73)

Researchers are attempting to construct more accurate diagnostic tools. Stratton and colleagues report that, “[s]everal Centers for Disease Control (CDC)-sponsored FAS projects are working to develop screening check lists. [In the absence of other reliable tools] [p]hotographic pattern recognition has proven up to now to be a better way to teach the facial gestalt of FAS” (p. 76). For instance, Streissguth and colleagues (1998) report on a Fetal Alcohol Behaviour Scale (FABS) that would describe the behavioural aspects of FAS and FAE:

It identifies many of the subjects with known or presumed prenatal alcohol exposure in detection studies using both prison and general samples. FABS scores also predict dependent living among adult patients with FAS/FAE. The FABS is uncorrelated with IQ, sex, age, race, and diagnosis (FAS versus FAE). (p.325)

In addition, new diagnostic criteria have been proposed by a government sponsored research group in the states:

A recent report from the Institute of Medicine (IOM) suggests a new category of prenatal alcohol exposure that would essentially replace FAE ...The classification, referred to as 'alcohol-related neurodevelopmental disorder' (ARND), focuses specifically on brain dysfunctions in the presence of significant prenatal alcohol exposure...Unlike FAS, ARND does not require the presence of facial or other physical anomalies. (Connor and Streissguth, 1996: 170)

Ann Streissguth is attempting to introduce this new terminology into the research literature, and into researchers' vocabularies, "Whenever possible, this article uses the diagnosis of FAS as defined by Sokol and Clarren (1989) and the diagnosis of ARND as defined by the IOM (1996).<sup>4</sup> However, the term 'FAE' is retained when it is the classification used by a cited reference" (Ibid.: 170).

Regardless of the label used, parents usually find that obtaining a diagnosis for their child is difficult and time consuming.

### **2.2.2 Difficulties of Diagnosis**

Once a child has been given a diagnosis of FAS/FAE, parents are able to channel their energy towards understanding the child's condition; they stop blaming the child, and are willing to accept that the cause of the behaviour is neurological damage sustained before birth (Kleinfeld and Wescott, eds., 1993; Stade, 1995). The diagnosis allows parents to place the child's challenging behaviours in context. It gives their experiences some meaning, and allows for a common bond between parents who are raising such children.

Parents, however, report difficulty in obtaining a diagnosis for their child (Kleinfeld and Wescot, eds., 1993). One parent, who runs a newsletter for parents of children with FAS/FAE, describes the common experience of many parents:

Many people write about the pain and frustration of finding a diagnosis, but all agree that the search for a knowledgeable diagnosis is well worth the effort. Diagnosing FAS/FAE can be difficult. Children with many other disabilities, including hyperactivity and attention deficit disorder, show similar symptoms. Some of these problems, such as lead poisoning, can be remedied with proper medical attention. A diagnosis of FAS/FAE, on the other hand, means irreversible brain damage. But the diagnosis creates understanding and begins the process of acceptance and adjustment. (Groupe Groves, 1993: 39)

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<sup>4</sup> (IOM 1996) appears in my References as Stratton, Howe and Battaglia, eds., (1996)



Whereas this parent knew that her children had FAS when she adopted them, this is not always the case:

We had the benefit of knowing from the beginning that our two children had a diagnosis of FAS. We were not really aware what this diagnosis would mean for all of us, but at least we knew we would encounter special needs along the way. Many parents have not had this advantage. They often face a difficult time of suspecting, denying, seeking a diagnosis, and then accepting and learning. I have received many letters from parents in various stages of this process. (Ibid.: 41-42)

Parents often have to wait from six months to a year for their child to be diagnosed at a clinic (Davis, 1994). The advantage of a diagnosis is that

[f]or most, it is an answer--an explanation as to why these children and adults have acted and reacted the way they have. It serves as a starting point for letting go of old expectations and accepting the reality of how things are going to be. Once the acceptance comes, steps can be taken to formulate a new plan. (Ibid.: 168)

Furthermore,

[i]t can be a catalyst for parents to: Seek additional education and information; Begin a process of personal recovery and healing for the mother and her family; Have more information and a 'label' to take to their child's school, so that the child will (hopefully) get more help with their education; and Motivate families to get involved in educating the public about FAS/FAE and lobbying for more local, state and federal moneys for prevention and family assistance programs. (Ibid.: 9)

Unfortunately, children with FAE, who often lack the facial features typical of FAS, are at a high risk of "falling through the cracks" at school because they look like all the other students, and therefore are not recognised as disabled (Davis, 1994: 3-4). Davis outlines three reasons why a family may not get a diagnosis, even though they try: there may be no trained expert in the area; the clinician may have a long waiting list; and there may be insufficient information about alcohol consumption in the history of the birth mother. She is optimistic that

[a]s more research is done and FAS/FAE is better understood by our society, getting a diagnosis should become easier and more services should be readily available to children with FAS/FAE and their families. (p.10)

Stade (1995) considers the consequences of the reluctance of the medical community to diagnose and therefore “label” individuals as FAS/FAE:

while health literature over the last decade has warned about the dangers of labelling ...no research has examined if reluctance to label has influenced diagnostic decisions. No research has examined the consequences of not labelling. (pp. 89-90)

Edgerton, an anthropologist, examines labelling in the context of the process of socialization. He sees labelling as a lifelong process which involves the child, the family, and society. He points out that the effects of labeling have not been well studied. For instance, what are the effects of experiences which occur before the label is imposed, and what are the effects of carrying more than one stigmatising label? Here he is discussing the issue with regard to mentally retarded children:

Labeling is not simply a clinical or administrative event, it is a process of socialization. The complex of expectations and practices that typifies socialization for incompetence often begins with restrictions that deny mentally retarded children access to experiences that are commonplace for ordinary, nonretarded children. For the retarded child, certain experiences are defined as ‘too dangerous’ or ‘too difficult’... (1984b: 36)

The medical community is in agreement with parents regarding the importance of diagnosis. It allows them to communicate with parents and with other doctors, to study the causes and mechanisms of damage, and to guide treatment (Stratton, Howe, and Battaglia, eds., 1996).

There can be drawbacks to a diagnosis. Wilbush (1988) describes how classifications, such as those of medical nosologies,<sup>5</sup> are constructed in subjective ways in that they serve a certain purpose; they are tools for the quick diagnosis of diseases. The criteria for FAS diagnosis are criticised by parents for their rigidity and inability to include their children. They speak of children being pigeonholed, of being excluded from services and support because they have not received the “right” label (Raymond, 1997). A vital point which must be made is that currently, in our education system, an IQ score (based on standardised testing) of 70 or less is required for services such as a classroom aide. In other words, it is independent of an FAS or FAE diagnosis. If they have a higher IQ children receive limited special education programming. Finally, there is always the potential for stereotyping based on an FAS or FAE label.

Another drawback to diagnostic guidelines in general is that these typologies

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<sup>5</sup> Nosology is the branch of medicine dealing with the systematic classification of diseases.

become reified. The labels used in classification

assume an identity of their own, and can have tremendous influence on behaviour. Once classified, items are seldom reexamined; they form a superimposed grid which references all actions, pigeonholes opinions, even directs emotional responses. (Wilbush, 1988: 54)

Stereotyping based on labels can lead to the “self-fulfilling prophecy” and stigmatisation aspects of diagnosis mentioned above. Wilbush goes on to discuss the fragmented nature of medicine in which each body part or function is assigned a particular specialist.

Classifications of ill health divide the body into various sections to be treated by corresponding specialists such as the neurologist or haematologist. Orthodox nosology begins with the primary division into “physical” and “mental” diseases which “has drawn an intellectual curtain between those who care for the physical well-being of patients and those concerned with their ‘mental,’ often general welfare” (p. 56).

A most important consideration regarding the value of diagnosis is that

[t]he diagnosis should be a first step in developing patterns of interaction based on an understanding of the problem. The diagnosis of FAS is not an end in itself but rather a marker that more help, protection, and supervision may be needed. An FAS diagnosis is not an excuse for bad behavior but rather a guidepost for how best to evaluate and produce more adaptive behavior. (Streissguth, 1994: 75)

Finally, as knowledge about FAS/FAE reaches the general public, misunderstanding may lead to children being incorrectly “diagnosed” by unqualified individuals. Since many other genetically based syndromes mimic many of the features of FAS (Stratton, Howe, and Battaglia, eds., 1996), this diagnosis should only be made by a trained expert.

Usually several professionals are involved with the assessment of an individual:

FAS is not something that I want people to make a diagnosis of in the supermarkets. This is a diagnosis that is made by a team with the help of a pediatrician or a physician who is comfortable in the area of Alcohol-Related Birth Defects, and with a psychologist, with an interdisciplinary team, most often a speech and a language pathologist, and there needs to be community involvement. [This includes][t]he community health nurse, the social worker and, most importantly, the family. (Loock, 1994: 32)

## **2.3 Characteristics of People with FAS/FAE**

When discussing the typical characteristics of people with FAS/FAE, one must remember that this condition expresses itself differently in each individual. These characteristics have been established by researchers through testing, and caregiver reports on questionnaires, interviews and surveys. More parent and caregiver information is needed: only two studies (Stade, 1995; Raymond, 1997) have focused their research specifically on parents, and used in-depth interviews as their primary research instrument.

First, I will present a developmental overview of FAS/FAE from infancy to adulthood. I will then discuss some of the medical and educational studies which have documented their cognitive, neuropsychological, and behavioural difficulties.

### **2.3.1 Developmental Overview**

The following overview of the developing child who is affected by alcohol is based on Streissguth and Randels (1988), Streissguth and colleagues (1991), and Streissguth and colleagues (1996).

Infants with FAS/FAE are usually of low birth weight. They may be excitable, have a poor sucking reflex, and be fitful sleepers. There may be additional problems such as hypotonia (low muscle tone) and increased irritability.

In early childhood, they are often alert, talkative and friendly. They have been described as generally healthy, short and extremely thin, and very active. Children with FAS/FAE may have severe temper tantrums and difficulty making transitions between activities. More than half show hyperactivity, and many are over-sensitive to touch or other stimulation. They often have attentional deficits, fine motor difficulties, and developmental delays. Recurrent ear infections, eye problems and congenital anomalies may be present and must be monitored. Their apparent skill level is often higher than their tested level of ability, especially in IQ and verbal skills. During early childhood they may appear to be catching up to their peers but will face difficulty in later life.

In middle childhood, children with FAS and FAE are often hyperactive, distractible, impulsive, and have memory difficulties. They are usually friendly, but often lack the social skills to make friends or stay away from strangers. In school they often have trouble making transitions from one activity to another, and predicting the consequences of their own and others' behaviour. In the primary grades, these children's developmental deficits may result in academic problems. Their tendency toward concrete thinking interferes with learning concepts, especially mathematics.<sup>6</sup>

The effects of prenatal alcohol exposure are carried into adolescence and adulthood. Children with the highest IQs have been found to have the greatest problems adjusting to life as adolescents and adults. They have emotional problems, run away

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<sup>6</sup> While an inability for "abstract" thought is often mentioned in the literature, it is more correctly termed "conceptual" or "symbolic" thought (Wright, 1984).

from home, drop out of high school, and have a high rate of teen pregnancy. These children are not recognised as having a mental handicap by their teachers, and are accused of being inattentive and poorly motivated students.

According to Streissguth and colleagues (1996), IQ scores remain relatively constant through adolescence and adulthood. Their memory problems, poor judgment, and difficulty linking actions with their consequences lead to allegations of dishonesty, being manipulative, and even “lack of a conscience.”(Ibid.) Adults with FAS/FAE have high rates of alcoholism and mental illness (Famy et al, 1998). They have trouble holding down jobs, and, because of weak organisational skills and poor sense of time, often run out of money or forget to pay their rent. If unsupported by friends or family, they may end up destitute and homeless (Streissguth, Moon-Jordan and Clarren, 1995). Many are drawn into criminal activity to support their addictions (Ibid.).

### **2.3.2 Educational, Behavioural and Social Disabilities**

Parents describe their children’s learning disabilities and behaviour problems as the most troubling; any physical problems were dealt with routinely, and were not a major source of distress (Stade, 1995). Furthermore, researchers who have interviewed parents of children with mental retardation and chronic illness, found that those with children who also had behavioural problems such as hyperactivity or aggression felt the most stress (Floyd and Gallagher, 1997). Therefore, research which examines only the medical aspects of FAS (e.g., Loney, 1997) while important, only scratches the surface of the problem.

A paediatrician expresses a similar view:

From a pediatric point of view it is not primarily the major or minor malformations or the growth restriction that is most important. The functional disturbances that strike the central nervous system have the greatest impact on the individual and society. (Aronson and Olegard, 1985: 138)

Functional abnormalities include impaired fine motor skills, neurosensory hearing loss, poor tandem gait, and poor eye-hand coordination as well as:

Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition [self-awareness about how one thinks]; specific deficits in mathematical skills; or problems in memory, attention, or

judgment. (Stratton, Howe, and Battaglia, eds., 1996: 5, emphasis added)

While many researchers speak in terms of individuals with FAS/FAE having developmental delays, parents explain that the term “delay” is incorrect, because their children have limits on how much they can achieve in certain areas such as mathematics (Raymond, 1997). “Delay” implies a slowing of development, and a catching-up period; these children reach a “peak” in learning (Ibid.).

Nanson and Hiscock (1990) found that, when given psychological tests, children with FAS/FAE, aged five to twelve, had attentional deficits similar to children with attention deficit disorder (ADD). This is true for adolescents (Olson et al., 1992) and there is some evidence that this persists into adulthood (Streissguth et al., 1996). Recent research, however, has found that the attentional problems found in FAS/FAE differ qualitatively from those in ADD (Coles et al., 1997). This research used the model for assessing attention functioning devised by Mirsky and his colleagues. While the traditional method of assessing attention functioning consists of checklists which describe behaviours, clinical judgement and observation, Mirsky’s model assesses four specific factors: the ability to focus, the ability for sustained concentration, the ability to encode (involving sequential memory and learning) and the ability to shift from one subject to another without undue stress. Neuropsychological tests were used to measure the four aspects of attention. The researchers state that,

[t]he advantage of examining attention in this way is that it provides a method to discriminate different functions underlying the child’s behavior and performance and, therefore, may help in refining treatment and educational interventions. If children with a diagnosis of FAS or evidence of other alcohol effects are more impacted in specific brain areas...certain neuropsychological measures [should be] performed less well. If these functions can be identified, deficits characteristic of alcohol exposure may be specified. (Coles et al., 1997: 150)

The researchers found that children with FAS appeared to have deficits in visual spatial skills, encoding information, and flexibility in problem solving. On the other hand, children with ADHD (Attention Deficit Hyperactivity Disorder) were best identified by behaviour checklists and measures of the ability to focus and sustain attention (Ibid.). Furthermore, while Ritalin helped both groups focus their attention, those with FAS/FAE remained unable to encode the information they attended to, or to use new information meaningfully in problem solving (Coles et al., 1997).

Regarding cognitive functioning as measured on IQ tests, Habbick and colleagues (1996) found that of 166 individuals with FAS who were given standardised intelligence

tests, 134 (80.7 percent) were in the borderline or retarded ranges (IQ 55 to 79) (p. 205). Similar findings were reported by Streissguth and colleagues for a larger sample. They found that :

IQ data were available on 473 clients in the Primary Disabilities Sample: 178 have a diagnosis of FAS and 295 a diagnosis of FAE. Clients with FAS have a mean IQ score of 79, with a range from 29 to 120. Clients with FAE have a mean IQ of 90 with a range from 42 to 142. Twenty-seven percent of the clients with FAS and 9% of the clients with FAE have an IQ of 70 or below. (Streissguth et al, 1996: 20)

Individuals with FAS/FAE have short term memory problems (Male, 1995), and memory problems similar to patients with Huntington's disease (Connor and Streissguth, 1996) which may be linked to abnormalities in the basal ganglia. Children with FAS have problems remembering objects and produce more spatial distortions when drawing them (Ibid.). It is hypothesised that these difficulties may be the result of damage to the hippocampus since patients who have had part of the hippocampus removed to relieve epilepsy make similar errors.

Jenner (1994) explains that

[I]anguage and speech impairments are a characteristic of children with FAS/FAE that is generally described under central nervous system dysfunction; however, Bert and Bert (1992) maintain that language and speech problems are so characteristic in children with FAS/FAE that they should be emphasized as a separate criterion with 'symptomatology in their own right' (p. 4). (p. 12)

Both receptive and expressive language are affected, but expressive language more so. In addition to experiencing delay in acquisition of language and speech, their speech may contain little content (Ibid.). Furthermore, pragmatic and syntactic deficits occur in the speech of children with FAS/FAE. They may also have difficulty articulating their words (Jenner, 1994).

## **2.4 Raising Children with FAS/FAE**

Researchers have estimated the annual costs of providing medical and educational resources for people with FAS in the United States (based on the rate of one case per 1000 live births) at over two million dollars (Abel and Sokol, 1991). This figure does not include expenditures for mental health, social services, and the justice system. Apart from the monetary costs, the social costs to individuals, families and communities of lost potential and productivity is tragic.

Children with FAS present major challenges for their families. The parents who have written about their experiences are mature, articulate, and have the material resources

to procure any services which are available for their children. However, they are stretched to their limits, both emotionally and physically. Below I present the words of parents which appear in books written by them and for them. First, a mother of several adopted children with FAS/FAE explains how people's misunderstanding of her children causes the most pain. She describes the role she takes in trying to help her children succeed against all odds:

Without special help, my children do not have the ability to follow society's rules, especially the unwritten ones...But the more profound tragedy for all these children, and certainly for mine, is that their neurologically dictated social behavior appears to be--in the eye of the beholder--deliberate and wilful misbehavior...They see his behavior as under his control, as actions that should, can, and will be changed if we but try hard enough and long enough, using the right techniques. This view of alcohol-affected children sets us up--both the children and ourselves as parents--for long-term frustration, low self-esteem, social isolation, and ultimate failure as we try to accomplish the impossible...[I decided that] I would have to acquire the skills of advocacy. I would have to acquire the skills of interpretation to make their behavior, while not always acceptable, at least understandable and logical to other people. I would have to acquire a thorough knowledge of alcohol-related birth defects. To have a rough knowledge of FAS or FAE was not enough. Once I truly understood what was meant by such ideas as 'generalization,' 'cause and effect reasoning,' 'inferential thinking,' and 'concept formation,' I began to look at my children and their behavior in an entirely new light...I stopped seeing my children as noncompliant and started seeing them as noncompetent. (Lutke, 1993: 73)

Michael Dorris, after many years of parenting alcohol-affected children became very disheartened. Here, he reflects on his own situation and anticipates a possible future which awaits us if the issues of alcohol abuse are not addressed seriously:

The grind doesn't get easier and it doesn't go away. FAS victims do not learn from experience, do not get well. Louise [his wife] keeps a diary and a while ago she glanced back over the past four years. That can be dangerous, because there are some things you don't notice until you take the long view. It turned out that as a family we hadn't had a single period longer than three consecutive days in all that time when one of our alcohol-impaired children was not in a crisis--health, home, school--that demanded our undivided attention. It often seems to us that their problems define our existence as well their own....(Dorris, 1994: 99, emphasis added)

While they do not paint such a dismal picture as Dorris, many parents write about the



frustrations they face. To give just one example,

...Even when you have a diagnosis, others may not accept or even remember it. My own daughter's well-meaning special education teacher kept insisting her slow cognitive pace was just laziness. Her memory problems also became an issue, and it took more than half a year to convince the teacher that my daughter was not forgetting the multiplication tables on purpose. What it took to change this teacher's awareness was time, my own educational efforts, the teacher's experience with my daughter, independent testing results, and conferences with evaluators and the special education supervisor. But it was worth it. When the teacher's understanding of the situation changed, my daughter's attitude toward this teacher and school itself improved. (Groupe Groves, 1993: 42)

While raising these special needs children can be emotionally and physically exhausting, some parents adapt to the continual round of crises. The key, it seems, is to relinquish the idea that parents alone could, or should, attempt to raise these children unaided. It is necessary to cultivate a network of caring and knowledgeable adults who can act in a supportive manner. These can include neighbours, coaches, teachers and family friends, as well as health professionals. Another important consideration is to focus on the children's strengths. Focusing on the positive may seem a difficult task to the outsider, after surveying the clinical literature which speaks of these children in terms of deficits and disabilities. Parents, however, as the "experts" on their children, can see beyond their limitations. One mother tells her story in a newsletter which acts as a support network for other parents:

Our son is now nineteen years old and a high school graduate, whew! There were times I thought we would never make it that far. He actually finished school on a real positive note, having joined the marching band and learned to play five instruments. The experts said he could never do it. We have always fought the school's effort to limit him, always hoping he could reach some of his dreams. While reality clearly shows his limits, I am glad we withheld our doubts and fears and allowed him to try the band. The doctors always told us that musical instruments would prove too frustrating for him, but he proved the doctors wrong.

I guess I thought 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 can not or will not try to accept him. He doesn't want pity and there's no mercy, not in the job market or any place else!

He finally found a job this summer at Disneyland and we're hoping it will continue into fall. The world expects him to act like an adult and his brain doesn't know how. It's heart rending to watch him try to function socially and suffer rejection and misunderstanding. (Groupe Groves, 1993: 49)

The editor of this newsletter shares some advice regarding the need for a positive outlook and strong support network, which comes from her own experience and that of other parents who have written to her over the past few years:

Many children with FAS/FAE thrive in individual sports including swimming, gymnastics, dance, and track. For some children, the repetitive motion in activities such as swimming provide [sic] a soothing effect similar to the stress reduction obtained through perseveration. Taking part in athletics uses excess energy, builds self-esteem, develops life-long enjoyment, and provides opportunities for social life. Try to find a mentor in your child's sport, taking care to provide some supervision to prevent taking advantage of the child's vulnerability ...[Furthermore], many children with FAS/FAE have creative talents in different areas, perhaps because they see the world differently. Often children have musical abilities...Some children have artistic abilities in drawing and pottery. Creativity may be expressed in inventing things, storytelling, and even cooking. Adapt to what the child can do ....Often children with FAS/FAE are good at building and constructing with Legos [sic], blocks, and anything they can take apart and put together...Many enjoy gardening with its watering, raking, weeding, and planting.

...Keep the strengths of the children in mind. Even though children with FAS/FAE may have severe memory problems and some cannot remember the multiplication tables or follow lengthy directions, they often have an excellent long-term memory for events and activities. My children often astound me with their memories of past family activities and our previous homes. (Ibid: 51-53)

While this passage has explored some of the strategies parents use to create support for themselves, and to meet their children's needs, the next section will discuss treatment strategies and educational interventions which have been used by educational and medical professionals.

## **2.5 Treatment Strategies and Educational Interventions**

According to an expert in the field of FAS research, although they have many difficulties, individuals with FAS/FAE should not be seen as hopeless cases:

We do not give up on children with cerebral palsy; we devise intricate plans to help them with their disability. We do not give up on children who are deaf; we teach them sign language, we fit them with hearing aids, we give them the special help they need to lead as normal a life as possible. The same should be the case for children with FAS. Our goal is to help them develop as far as they can but also, by recognizing their disabilities, to protect and nurture them so they are not overwhelmed by unrealistic expectations. (Streissguth, 1994: 73-74)

The procedure for obtaining help includes an accurate diagnosis then, “the next step would be to get a psychological evaluation in order to understand the individual’s strengths and weaknesses” (Ibid.: 74).

By treating primary disabilities as they arise (cognitive and neuropsychological deficits), secondary disabilities can be avoided (Streissguth, 1994). These “secondary disabilities can include early school drop out, alcohol and drug abuse, mental illness, suicide attempts, joblessness, homelessness, and early and unplanned pregnancies” (Ibid. 74). I believe that this perspective is helpful, because it emphasises the fact that these problems are preventable, rather than inevitable. However, including homelessness and joblessness in a list of “disabilities” certainly medicalises life situations which are influenced by societal factors, and encourages the medicalization of poverty.

Regarding specific types of psychological treatments:

...it is important to consider the mental health needs of patients with FAS/FAE and to consider the mental health needs of their caretakers...[and] ...In general, we have not observed that the usual modes of play therapy, insight-oriented therapy, or group therapy are particularly effective with patients with FAS/FAE, although no research has been carried out. These patients do, however, respond well to a counselor or advocate who can provide clear feedback on the consequences of their behavior and can offer helpful suggestions....In general, techniques utilizing a positive rather than a negative mode of behavior change seem most effective. There is no research on the efficacy of medications for treating persons with FAS/FAE. Treatment outcome research is urgently needed. (Streissguth, 1994: 75)

Unfortunately, treatment facilities and programs are inadequate:

It is our impression that there continues to be an absence of programs geared toward the adolescent with FAS/FAE, both

in the school, in the community, in alcohol and drug treatment and prenatal care programs, and in the juvenile justice and criminal justice system. (Ibid.)

There is still little data on the effectiveness of specific treatments:

...there have been no systematic studies of the benefits of early intervention for infants and young children with FAS/FAE... So far, no empirical research provides insight on how to ameliorate the specific cognitive disturbances accompanying FAS and ARND...[But cognitive rehabilitation therapy used for people with traumatic brain injury may be helpful for people with FAS/FAE.]...anecdotal reports suggest that using behavioral strategies that use high levels of structure, concrete (rather than abstract) rules and consequences, and close caretaker supervision may help the FAS patient... [Furthermore],...positive behavioral management involves bringing about behavioral change through systematic management of the behavioral consequences. (Connor and Streissguth, 1996: 173)

Positive behavioural management has been used successfully with autistic children, but has yet to be researched in individuals with FAS/FAE (Ibid.). Finally,

...medications are another avenue of intervention that needs to be systematically examined, particularly in terms of the high frequency of attentional problems in children with FAS/ARND and the significant levels of depression noted in adolescents and adults. (Ibid.)

According to Davis (1994) the following interventions have been useful in the schools. These suggestions have been restated in various ways by parents and educational researchers such as Raymond (1997), and Jenner (1994):

At this time, we know that the most students with FAS/FAE function best when: the classroom is small (eight to ten students); it is self-contained; there is minimal change; stimulation is kept at a minimum; rules and guidelines are clear and consistent; expectations are realistic; there is as much one-to-one attention and supervision as possible (three adults to eight students is recommended); positive reinforcement is used; curriculums [sic] allow the student to be successful the majority of the time; students' feelings are acknowledged and there is a plan for them to be expressed in appropriate ways; and communication between teachers and parents is clear and open. (Davis, 1994: 38)

Students with FAS/FAE find it difficult to:

Stay on task; refrain from being in constant motion; refrain from being disruptive; work independently for long periods of time; distinguish right from wrong; learn from their mistakes; use good judgment; control their impulses; and retain what they learn from one day to the next. (Ibid.)

Teachers should be aware that students with FAS/FAE have the following characteristics in common with students with ADD and other behaviour disorders. They are hyperactive, impulsive, and find it difficult to stay on task or complete tasks. These children are disruptive, have poor social skills, demand lots of attention, and have learning disabilities (Davis, 1994). Davis' comment that they "show a disregard for rules and authority" (p. 39) must be interpreted in the light of Lutke's comments, above, that her children are "noncompetent," not "noncompliant."

However, a standardised curriculum for teaching students with FAS or FAE should not be developed since there is such a broad range of abilities among students (Burgess and Streissguth, 1992, from Jenner, 1994). Each student with FAS or FAE should have a curriculum uniquely designed for his or her educational needs. This is standard practice for student's who have been identified as having special needs: an individualised educational plan (IEP) lists the modifications to the standard curriculum, and any special programs required, as well as setting long and short term learning goals (Nowak, 1997).

According to Jenner's (1994) review of educational policy in Saskatchewan regarding FAS/FAE, researchers suggest that some existing methods of special education are effective for those children with FAE who have cognitive impairments. These include regular programs, programs in which the regular curriculum is adapted to the child's needs, alternative programs, and any combination of these.

Jenner goes on to explain that "functional skills programming" is suggested for students with severe cognitive impairments. These functional skills include life skills and vocational skills, and should be aimed at preparing them for adult life. These programs would be suitable for those with FAE, who have only mild cognitive impairment but poor life skills. Researchers have recommended that instead of using IQ level as a criterion for special services, adaptive functioning should be the primary criterion.

People with FAE have poor communication skills which impair their interpersonal relations. Therefore, these skills should be integrated into the functional skills programming. It must be remembered that communication includes both verbal language and non-verbal modes such as body language. As well, "effective communication involves the use of a style of communication which is appropriate to the context" (Jenner, 1994: 40).

It is vital to note that most educational systems in North America do not recognise

FAS and FAE as distinct disabilities; consequently, these conditions are not placed in a separate funding category. Students with FAS/FAE are usually categorised as being mentally challenged, or as having a behavioral or emotional disability (Jenner, 1994).

Summing up the research on structured classroom management, Jenner (1994) notes that educators have found that students with ADHD show fewer symptoms in highly structured settings and when they have one-on-one help from an adult. Structured classrooms have the following characteristics. First, good behaviour and performance are expected. Second, the rules are simple. Third, there are explicit positive consequences for good behaviour and performance. Furthermore, it is assumed that the expectations that the teacher has for the student are at an appropriate level such that the student can achieve some success. Next, there must be consistency in applying the rules and providing rewards. Finally, there should be mutual respect and trust between the pupils and the teacher. By following these guidelines, teachers can ensure repeated, predictable interactions, which will help the child gain confidence (Ibid.).

Social skills training is needed when children have social or emotional deficits. Role playing, direct instruction role play and modelling are often used to teach social skills. Social skills training would ideally take place in the regular classroom with the whole class rather than separating those children with social or emotional problems. The more socially adept peers would be able to act as role models for the less skilled students (Jenner, 1994)

Junior high and high school is a difficult time for many students with FAS/FAE (Raymond 1997). This mother, and educator, outlines their needs during the vulnerable adolescent years:

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-affected adolescents need an individualized program that addresses their social behaviors 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: 91)

Raymond (1997) reports that in her study

[a]lthough frustrated and unhappy with the services their children were receiving at one time or another, all of the participant parents felt they did not always have an effective avenue to influence change. They also perceived that the higher their children's grade level, the more alienated they felt from the decision making process.

By the time their children entered high school, seven of the ten respective parents had become so disenchanted with their marginalized state that they discontinued attempts to interact with the school. This resulted in decisions made about their children's programming, grades, and performances that these parents did not always consider to be appropriate or productive. (p.97)

This section has summarised the current treatment and educational interventions used with individuals with FAS/FAE. Next, I will examine some research issues identified in the literature.

## **2.6 Research Issues**

In this section I will briefly outline several issues related to FAS research and prevention efforts. In order to bring society's attention to FAS/FAE, the extent of the problem must be clearly demonstrated. Epidemiologists are attempting to gather accurate statistics in order to quantify the frequency of the occurrence of FAS/FAE and the number of affected individuals. Furthermore, certain groups of women have been identified as being more "at risk" than others for having a child with FAS/FAE. Research undertaken in this area can ensure that prevention efforts are targeted to those most in need. They also document the underlying societal conditions such as poverty, poor housing and inadequate health services that these women face. Since FAS/FAE is totally preventable if a pregnant woman does not drink, and harm to the fetus can be minimised if a pregnant woman who is abusing alcohol stops drinking, alcohol treatment programs are an essential feature of prevention efforts.

### **2.6.1 Epidemiology of FAS/FAE**

The first issue is the need for better epidemiological data which would demonstrate how many cases of FAS/FAE occur over a specific time period, in specific geographic areas or particular populations. While "[e]pidemiological data is important with respect to the prevention of FAS),...[n]o firm conclusions can be drawn regarding the epidemiology of FAS in the general Canadian population and among the Aboriginal minority in Canada" (Loney, 1994: 341-343). This is also true for the United States (Abel, 1990). Estimated rates of incidence of FAS are .33/1000 live births worldwide (Abel and Sokol, 1991), and .585/1000 live births in Saskatchewan (Habbick et al., 1996), while FAE is estimated to occur at three to four times this number (Ibid.). This is an important research issue since, "Incidence rates are necessary to target prevention strategies and evaluate their impact, [and p]revalence rates can guide community planning for secondary and tertiary prevention activities, such as appropriate educational and social services" (Loney, 1994: 341-342).

## 2.6.2 High Risk Groups

It is now well established that FAS/FAE is a complex condition that occurs due to interactions among environmental, biological, and social factors (Stratton, Howe, and Battaglia, eds., 1996). According to this model, some women are more likely than others to have a child with FAS/FAE. Abel has proposed that poverty is the major risk factor for FAS in the presence of heavy drinking during pregnancy (Abel, 1990). While the relationship between poverty, heavy drinking in women and FAS is complex and not well understood (Loney 1994), other researchers have confirmed this relationship.

Rosette and Weiner, in their 1984 study, found that pregnant women who drank heavily (a minimum of one and a half drinks daily and at least five drinks on some occasions) displayed the following characteristics: they were older, were not first-time mothers, smoked and used other drugs. Furthermore, they were exposed to more social stress than non-drinkers, were more likely to be single or divorced, and associated with others who drank heavily (Ibid.). Similarly, while Looock (1993) warns that any woman who drinks while pregnant is at some risk of having a child affected by alcohol exposure (no safe level of alcohol intake has been determined), she explains that those at highest risk fall into the "four p's": "living in poverty who have poor prenatal care, poor nutrition and are multiple ... or polydrug users"(p. 35).

Populations of women fitting this profile have been identified in the downtown east side of Vancouver (Looock, 1993), and a primarily African American inner city community in the United States (Abel, 1990), and rates of FAS/FAE were high in the newborns of both these groups. These findings should not be interpreted to mean that middle or upper class women do not produce children with FAS/FAE.

Sampson and colleagues (1997) report on two studies of the incidence of FAS, one in Cleveland and the other in Seattle. In a study of pregnant women who received care at a Seattle hospital which took place from 1974-1975, the incidence of FAS was 2.8 per 1000. "The sample, although heterogeneous, was primarily white, married, and middle class..."(Sampson et al., 1997: 321).

In contrast, "[t]he sample for the Cleveland Fetal Alcohol study was drawn over the period 1979-1981 from a hospital that served mainly poor, inner-city patients..[and] the incidence rate was 4.6 per 1000" (Ibid.).

Poor social and economic conditions exist in isolated Aboriginal communities in northern Saskatchewan (Feather, 1991), and northern Ontario (Young, 1994) where poor health care, high unemployment, low wages, inadequate housing and sanitation, high teenage pregnancy rate, poor nutritional status, and patterns of heavy drinking have been identified. Similar conditions exist for many Native people in urban centres in Canada (Waldram, Herring and Young, 1995). However, this should not be seen as an excuse to further marginalise communities, by labelling them as fundamentally sick and dysfunctional, and beyond hope (Ibid.).



The Centers for Disease Control (CDC) in the United States found that according to nationwide birth defects statistics (on 21 percent of births for 1981 to 1986), Native Americans had 33 times greater risk of having a child with FAS compared to whites (Stratton, Howe, and Battaglia, eds., 1996).

Loney, Green, and Nanson (1994) declare that it is time to abandon the disease-prevention model of FAS, and to see that “its main cause--excessive alcohol consumption by pregnant women--is embedded in everyday patterns of living, which are reinforced by social, economic and cultural factors”(p.248). They suggest that alcohol abuse by pregnant women can only be addressed by examining the problem of alcohol abuse in the general population. While this is a helpful development, Loney, Green and Nanson do not define what they mean by “cultural factors.” They do suggest that loss of cultural identity may be a factor in Native people’s abuse of alcohol. While this probably is an important factor in the loss of self esteem and feelings of hopelessness which may lead to alcoholism, researchers should be wary of cultural explanations:

The past emphasis on cultural or biological explanations for Aboriginal health has served primarily to reinforce existing (and erroneous) stereotypes of Aboriginal Canadians, particularly by concentrating on perceived deficiencies, vulnerabilities, and weaknesses. These approaches have contributed little either to the understanding of Aboriginal health or to effective solutions to actual health issues. Indeed, they have often empowered the analysts and health professionals while portraying people as solely responsible for their own misfortunes. It could be argued that these theories tell us more about the normative assumptions of the researchers than about the problems they purport to explain. At the very least, neither biological nor cultural explanations encompass an Aboriginal perspective, and both support the construction of an image of Aboriginal communities as fundamentally sick and irretrievably out of control... [Biological and cultural factors should not be ignored, but a]ny approach which fails to consider Aboriginal people as active in response to their colonial situation, rather than simply as passive victims, will fail to comprehend not only the past changes in health status and health care, but more importantly the future direction that will be taken in these areas.(Waldram, Herring and Young, 1995: 269-70)

In the anthropological tradition, the cultural realm encompasses the social and economic realms; in this holistic framework all behaviour is “cultural.” Individuals, however, are both shaped by and act upon their cultural world. Nevertheless, anthropology does not see culture as a causal agent. As Geertz reminds us, “culture is not a power, something to which social events, behaviours, institutions, or processes can be causally attributed; it is a context, something within which they can be intelligibly--that

is, thickly--described" (Geertz 1973: 14). The following conclusion should be interpreted with this advice in mind:

There is evidence that Native Indian children are disproportionately represented among diagnosed FAS cases...Whether this represents under-diagnosis in the general population, over-diagnosis in the Native Indian population, or increased risk due to increased alcohol consumption and related socioeconomic and cultural factors has yet to be fully determined. (Loney, 1994: 343)

### **2.6.3 Alcohol Treatment and Prevention of FAS/FAE**

The multifactorial approach taken by the IOM (Stratton, Howe, and Battaglia, eds., 1996) and Feather's model of social health (1991) agree with the above definition of culture in spirit. An experienced researcher in the field outlines her approach to treating these "at risk" women:

Both alcoholism treatment and birth control are important issues, but, for these to be effective, many additional problems may have to be addressed, including stable housing, protection from abusive relationships, financial security and ongoing medical care. (Streissguth, 1994: 61)

Recent evidence from Saskatchewan has shown that the public health message is not reaching pregnant women who are drinking heavily, since FAS incidence has remained stable for twenty years despite numerous prevention efforts (Habbick et al., 1996).

As part of primary prevention efforts, our staff at ABCDP[Alvin Buckwold Child Development Program] have made numerous presentations to health professionals as well as to public groups. The Saskatchewan Institute on Prevention of Handicaps (SIPH), which is also housed at the Kinsmen Children's Centre, has emphasized prevention since the early 1980s, and since that time its FAS Prevention Program has included hosting a provincial conference in 1985, public service announcements for television and radio, newspaper and magazine articles, and community presentations (approximately 50 per year). The Institute developed FAS information kits in 1985, and in the last four years alone over 2,000 have been requested. The Institute and the ABCDP surveyed provincial paediatricians and family practitioners (Nanson et al., 1995) and demonstrated a high level of awareness of FAS in those groups. (Habbick et al., 1996: 206)

Conversely, American researchers recently stated with confidence that "the public health message about the consequences of drinking during pregnancy has been effective [since

drinking during pregnancy has decreased]” (Day, 1995: 1614). However, they admit that the majority of women in their sample were not heavy drinkers.

Both Day (1995) and Habbick and colleagues (1996) suggest targeting high risk women with effective prevention programs. Habbick et al. stress the need for culturally sensitive programming, given the high number of Aboriginal women who are estimated to be “at risk” in Saskatchewan.

According to Rosette and Weiner (1984), when counselling women about the effects of drinking while pregnant, the attitudes displayed by the health professional are important. Information conveyed in a supportive manner rather than a critical and negative manner is more conducive to behavioural change. The two approaches are illustrated below. The negative approach includes warning the woman of serious hazards; reprimanding the woman about responsibility to the fetus; castigating the woman for being a bad mother; and emphasizing the complications of intoxication.

The positive approach would emphasise the woman’s ability to reduce risk; support her maternal desires; promote confidence in her potential to be a good mother; and discuss the benefits of sobriety with her. They go on to say that most women are aware that drinking can harm the fetus, but do not always put their knowledge into action, and that media campaigns do not reach the heaviest drinkers who are most at risk (Ibid.)

While not only being of questionable efficacy,

warnings imply a simple, rational choice can be made, making it easy to ignore the complex social, psychological and physical dependency factors contributing to alcohol abuse. Simplistic warnings may reflect the view that alcoholism in women is a ‘moral weakness.’ Such a perspective may increase social stigma, already believed to be a barrier to women in obtaining or accepting intervention. (Loney, Green, and Nanson, 1994: 249)

Public policy, however, continues to push for warning labels rather than providing appropriate treatment services for women (Ibid).

A very negative approach can be seen in the tactic of placing stark and often disturbing photographs of clearly malformed children alongside audio or printed messages about the dangers of drinking when pregnant, in videos and posters designed by health professionals (e.g., CKCK, 1991)<sup>7</sup>

According to one researcher, society continues to take the easy road of blaming individual women for their drinking behaviour, turning to the justice system to control this behaviour through incarceration and mandatory treatment, and ignoring the multifactorial causes of all birth defects such as environmental and industrial contaminants

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<sup>7</sup> See also Steinmetz (1992) “Fetal Alcohol Syndrome” a photo essay in National Geographic.

(McCormack, 1996). Given the current direction of research, and prevention initiatives described below, this warning is somewhat overstated. The general public, however, is more likely to interpret prevention messages in a simplistic way, to use this information to stigmatise women who drink while pregnant, and for the time being, forget other causes of birth defects. These women may also be marginalised by professionals and labelled as difficult and beyond help:

Intervening effectively with chemically dependent pregnant women presents a difficult challenge for professionals. The lives of these high-risk women are typically characterized by chaos and denial of their condition. They have been labeled distrustful, unmotivated, and difficult--if not impossible--to reach. This image has been enhanced by a media focus on 'crack babies' and a social and political climate that suggests that drug-addicted mothers are responsible for a variety of social ills. Chronically drug-dependent women have become distrustful of 'helping' agencies, while many professionals have come to view these women as a hopeless population. (Grant et al., 1996: 3)

Several community wide initiatives aimed at raising awareness of FAS/FAE have been described in the literature (e.g., Asante and Robinson, 1990; May and Hymbaugh, 1989). Their objectives are to reduce drinking during pregnancy, and to identify children in need of intervention.

Massis and May (1991) discuss a successful treatment program which included community wide education, screening for "at -risk" women, and treatment in the form of detoxification and group and individual counselling, as well as birth control. The "Birth to Three" project in Seattle pairs women who were drinking during pregnancy with advocates who provide social support, and assistance in dealing with issues such as housing and employment (Grant et al, 1996). The children received early intervention, and protective services where necessary. This ongoing project is also reporting successful outcomes.<sup>8</sup>

Regarding initiatives in Saskatchewan, the Associate Minister of Health states that:

...the governments of Saskatchewan, Alberta and Manitoba have embarked on the development of an inter-provincial FAS strategy. Among other activities, Saskatchewan has committed to developing and sharing with other provinces, training materials about FAS for professionals working in youth and child welfare facilities. This is important work, as we know that children and young people with FAS display developmental and behavioural problems which must be addressed, to help them cope with their condition. Saskatchewan Social Services is currently preparing a manual

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<sup>8</sup> See also Grant, Ernst and Streissguth, 1996.

on FAS, and training is expected to begin in early 1999....Saskatchewan Health is also working with provincial alcohol and drug treatment facilities in an effort to offer pregnant women priority access to the programs and services they provide. (Junor, Personal Communication,1998)

Posters which display the message, "Fetal Alcohol Syndrome (FAS) exists in our community, let's Find A Solution" are on display in liquor stores in the province. A series of public service messages recently aired which conveys the same message. The following warning is printed on liquor store bags: Drinking While Pregnant May Harm the Baby. These initiatives were funded by The Saskatchewan Liquor and Gaming Authority and SIPH. These are very conservative measures which, if used in isolation, could lead to the stigmatization of women, as Loney, Green and Nanson (1994) noted earlier.

The literature examined to this point has discussed the clinical nature of FAS/FAE, explained how a diagnosis is made, described the difficulties of obtaining a diagnosis, outlined the effects of FAS/FAE on individuals and their families, discussed possible treatments, and explored some research issues. The next portion of this chapter will cover the literature related to the explanatory model.

## **2.7 Theoretical Literature**

This section will include studies of chronic illness and disability; the medicalization of FAE, discourse and illness narratives and the possibilities of a model of care in which patients (or clients) and their families play equal roles.

### **2.7.1 Chronic Illness and Disability**

Strauss and colleagues (1984) made some pioneering studies of the social context of chronic illness. The term 'chronic illness' covers a wide variety of conditions including heart disease, arthritis, mental illness, and disabilities. It can be defined as:

All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care. (Mayo, 1956 from Strauss et al, 1984: 1)

Strauss et al. stress that they place the various chronic diseases (such as cancer or multiple sclerosis) into the comprehensive category of chronic illness so that the similar problems and circumstances that people with these illnesses face in their daily lives can be examined. This information can then be applied to both the education of health care professionals to improve their ability to treat these people, and to help create more suitable

support services and health care policy:

the road to genuine accountability, to organizational responsibility, lies in the direction of discovering the more general biographical patterns and then in a concerted effort to respond to them... [Furthermore], most important in this process are the patient's views which must be taken into account by doctors and other carers...listen[ing] more closely to what patients think good care must include for themselves. (Strauss et al., 1984: 192- 193)

Many of the problems faced by the families in Strauss et al. (1984) are also faced by families of children with FAS/FAE. The framework proposed by Strauss, then, may be useful to clinicians and policy planners. A more recent volume (Anderson and Bury, eds., 1988) presents a series of qualitative studies of families dealing with specific chronic illnesses such as arthritis and multiple sclerosis. Patients are seen as "interdependent members of a social network, principally that of the family..[it takes the family as] the unit of experience and analysis" (Anderson and Bury, eds, 1988: 3). The various authors "underline that patients and families are knowledgeable agents, not merely the passive recipients of influences that irresistibly condition their conduct" (Ibid.). Their aim is to explore the complex and sophisticated decisions which patients and their families make to manage or control their illnesses. The contributors examine the strategies developed by both patients and families to cope with their daily problems.

For instance, Robinson's (1988) study of multiple sclerosis patients reveals the social dimensions of the diagnosis and management of a condition that, like FAE, is poorly understood, and has an uncertain course. Moreover, in reviewing previous research, he found that patients must advocate for themselves, research their condition, and negotiate with professionals. These activities are very familiar to parents of children with FAE who must perform them on behalf of their children:

...patients were engaged in far more active negotiation with their doctors over a long period of time, rather than passively accepting the doctor's judgement on the initial, and often inaccurate diagnosis of the patient...Patients, with what was subsequently diagnosed as multiple sclerosis, pursued a vigorous campaign to eliminate the frequent discrepancy between their own perception of what they felt was happening to them and the doctor's perception. The culmination of this process was a reduction in ambiguity and uncertainty about the disease for the patient. Patients made sense of their symptoms through a sustained and continuous process of negotiation which eventually resulted in their doctor's legitimating their symptoms as those of multiple sclerosis. (Robinson, 1988: 48)

Their search for information took many forms:

...[T]here is evidence to suggest that the uncertainties about the diagnosis had prompted the acquisition of this information in a number of ways. This process of information gathering on diagnostic status must not be seen as one which just hinges on the relationship between the patient and physician. Patients may discover their diagnosis through diligent detective work; by comparisons with others known to have the disease; through extrapolation from information in the media, including books; through research on medical records left unattended, or through inadvertent disclosures by paramedical staff...The cross-cutting network of relationships between patients, their families and their physicians at the point of revelation of the diagnosis creates a framework through which the past and future experience of multiple sclerosis is mediated. (Ibid.)

The patients in Robinson's paper had similar experiences to the mothers in this study in their innovative means of seeking information, and their negotiations with their physicians about the meaning of their symptoms, and the importance of a firm diagnosis to put a name to their problems. This article was helpful in pointing out the different reactions to the diagnosis: some reacted with shock, while most were relieved.

While this section has looked at the chronic illness literature, the next part of this chapter will outline some anthropological and sociological studies which shed light on the social context of families dealing with FAE.

### **2.7.2 Stigma, Stories and Support**

While this thesis focuses on the parents rather than the children per se, the characteristics of these children greatly affect the experience of the parents. Parents often describe how their children are stigmatised and marginalised by society (see Groupe Groves, 1993, above). These children are not only "different," they are anomalous; they defy simple explanation because they do not fit into established categories. This is summed up in the description of adults with FAE as "children in adult's bodies." Mary Douglas (1995) is an anthropologist whose research has explored the nature of anomalies using a structuralist approach. Emily Martin's work (1994) describes how individuals who do not fit our post industrial society's need for health, speed, and flexibility are quickly becoming an underclass who are devalued. This is highly relevant for the understanding of how society reacts to individuals with FAE.

Edgerton (1976, 1984a, 1984b, and 1984c) has completed several anthropological studies of the mildly mentally retarded, based on decades of qualitative research on one group of subjects. His books and articles provide rich descriptions of these people's lives. He provides insight into the way they manage their lives, and presents the significant finding that their definitions of happiness, satisfaction and quality

of life may differ from those of professionals such as social workers, and also those of parents, and social scientists. His portraits have much in common with descriptions provided by Streissguth and colleagues (1996) of adults with FAS/FAE.

An expert on FAS/FAE realises that “[p]arent support groups are instrumental in helping parents understand their needs, organise their behaviors, obtain better services and more understanding for their children, and share their own hopes and disappointments” (Streissguth, 1994: 75). Formal support groups, however, are not the only source of information and support for parents. The Internet, books written by other parents, and newsletters are important sources of knowledge and emotional support since they create communities of understanding, or as Frank (1995) calls them “communities of interpretation.” A mother of affected children who edits a newsletter discusses its scope:

In this chapter, I will describe the problems, feelings, and ideas that readers of this newsletter have shared with me. Some letters are from parents struggling to cope with their children’s needs and their own worries and emotions. Other letters come from grandparents or relatives who suspect a loved child has FAS/FAE. Some writers offer their own exciting discoveries such as a strategy, a medication, or an emotional attitude that has made a great difference for them and may make a difference for someone else. In this uncharted territory, we all benefit from communicating with others who have traveled this terrain. (Groupe Groves, 1993: 38)

Frank (1995) illustrates how illness narratives, or “self stories,” can be transformative for the teller, and can transform the listener who, in turn, becomes a teller who internalises, elaborates and then passes on the tale so that it reaches out in concentric circles. An illness narrative or self story is a story told to describe a traumatic experience which, according to Frank, validates the experience and reaches out to help others. An illness narrative can be a published account, or stories of other families which are exchanged in support group meetings, which can be equally powerful.

The most important story about FAS is *The Broken Cord* (Dorris, 1989). A mother of a son with FAS who has written a book herself, explains how the writing process itself helped her. She then describes the impact of *The Broken Cord* (1989):

Writing this book has been a very positive experience for me because it has made me aware of how much progress is being made in this field. That which has been known by researchers for some time is finally being embraced by the general public, especially since the book *The Broken Cord*, by Michael Dorris, was published in 1989. Mr. Dorris’ beautifully written story about the bittersweet life of his adopted FAS son, Adam, had something that readers could relate to. It was a catalyst for more and more people to come forward with stories of their own, resulting in the raising of public



awareness and the networking of thousands of other parents with children with FAS/FAE. (Davis, 1994: vii)

Unfortunately, Dorris did not have such a positive experience. Here he reflects on the influence of his book, and his new identity as a spokesperson for FAS which he assumed in the round of television and radio talk show interviews which followed the book's publication:

That's hardly the identity I expected when I became a father. I speak out publicly today as a living anecdote, a walking warning label, a Chatty Cathy doll who spews forth a version of the same cautionary tale whenever the string is pulled. Our unhappy personal chronicle, the struggle of many well-intentioned and initially optimistic people to alter for the better the life of one damaged little boy, has to the great surprise of my wife and myself become a kind of flagship sound bite for prenatal sobriety, and yet mostly my role is not to warn but to mourn--and that's easier done in private. To be known for one's saddest story is not the road to notoriety anyone would willingly choose. (Dorris, 1994: 101)

A feature article in the *Toronto Star*, "Children of the Broken Cord," profiled Dorris' story when it was published in 1989. Over the next few years, articles appeared in major Canadian newspapers which present the plight of teenagers and adults with FAS and FAE, and the frustrations of parents who are struggling to raise them: "Blocked at every turn" (Henderson, 1992); "Mom fights to help troubled son fit in" (Dunphy, 1994). While these articles portray people with FAS/FAE as tragic victims, they emphasise the bureaucratic roadblocks which parents face, and the inability of current programs and services to meet their children's needs. However, some newspaper articles have a more sinister tone. While FAS/FAE is devastating at the individual, family and community level, I contend that the use of specific language in the headline of the following article contributes to the stigmatization of individuals and their biological mothers. It reads "Program targets fetal alcohol curse: Federal money takes aim at inner city evils" (Mitchell, 1994: A17). Other reports describe the problem as a "plague" or "epidemic" (*Toronto Star*, 1992). An article titled, "The face of fetal alcohol syndrome," begins,

The police list of their 10 most wanted often reveals not only criminal details but striking physical similarities in suspects: flattened cheeks and noses, thin upper lips and cleft palates...Although chaotic backgrounds due to parental substance abuse, coupled with learning deficits, behavioural and developmental problems may contribute to problems with the law, Hall said there is often a parade of fetal alcohol adults showing up before the courts. (Bray, 1996)

Once these powerful images are entrenched in the minds and discourse of the general public, it is difficult to present a more balanced view of the problem. Stigmatization adds to the problems of people with FAE. This is another concern for parents; presenting accurate information about FAS/FAE to different audiences, in order to assist their children.

Nowak (1997) explores the way in which Internet sites and on-line support groups are democratising access to medical and other knowledge for parents of children with disabilities. The type of discourse, or way we talk about a phenomenon has a profound impact on how we approach it (Mitchell and Winslade, 1997). Kleinman (1995) explains how the medical discourse is taking over more and more aspects of our lives. The medical discourse which arises from a hierarchical medical system, is especially noted for its ability to place patients and their families in a subordinate position. Kleinman believes that through incorporating patients' stories or "illness narratives" into their care, doctors can improve their practices. The strategic use of language is a central issue in the conceptual model presented in Chapter Eight.

## **2.8 Summary**

This chapter has reviewed the literature on FAS/FAE, and some anthropological and sociological studies which will inform the theoretical framework of this thesis. The next chapter will discuss the methodology of the study.

## **Chapter Three: Methodology**

### **3.1 Introduction**

This chapter presents a detailed description of the methodology used in this research project. It elaborates the brief outline of the research plan discussed in Chapter One.

Multiple semi-structured interviews were used to explore the experiences of adoptive parents who are raising children who have FAE. The participants provided in-depth answers to the interview questions, in which they discussed many issues which they identified as most relevant to their day-to-day lives.

This research project is qualitative in nature. According to one experienced researcher, “the philosophy, purpose, and intent of the qualitative paradigm...is to discover in-depth meanings, understandings, and quality attributes of phenomena studied, rather than to obtain quantitative measurable outcomes” (Leininger, 1994: 97). Ethnography, phenomenology, grounded theory, and life history are some qualitative methods of research. This project uses the grounded theory methodology.

### **3.2 Conceptual Framework: Grounded Theory**

By using grounded theory methodology to collect and analyse the data, this study strives to document the process of raising these children. In this method, one does not begin a research project with a preconceived theoretical framework, but with a broad research question which defines the phenomena under study. Grounded theory studies generate models or substantive theories that are “grounded” or closely reflected in the data (Strauss and Corbin, 1990).

Grounded theory provides a method for both collecting and analysing qualitative data, and results in a substantive theory that explains a particular social process from the point of view of those undergoing the process (Ibid.). I chose grounded theory for its focus on process, and its ability to map out changes which take place over time. Moreover, in the case of families raising children with FAE, these changes take place in a fluid social, economic and political context, and grounded theory reaches out into these realms.

I was inspired to take this route after reading Stade’s (1995) thesis which explores the experience of raising children with FAS and FAE. Her study vividly portrays the emotional and physical strain which parents face in raising these children with special needs. She used a phenomenological approach, which aims to capture the meaning of an

experience from the participant's point of view at a precise moment in time (Morse and Johnson, 1991).

In her conclusion, Stade indicated some areas for future research which originated in important questions which her study raised but did not answer, such as: What are the effects of demographic factors (such as age and income) on the experience of parenting? and, Do the needs of parents change over time? I hoped to address these and other questions, and to discover the similarities and differences between the parents in Stade's study who live in southern Ontario and the Yukon, and the parents in my study who live in Saskatchewan. A detailed comparison of the findings of my study and Stade's can be found in the Discussion, Chapter Eight. Here I wish to make the point that by using grounded theory, I could obtain the rich data which is characteristic of small-scale qualitative studies (Leininger, 1994), but add the dimension of time, and broaden the social context in which the action takes place.

In the case of parents of children with FAE, the meanings of their experiences are created and modified in their interactions with their children, with other adults who work with their children in the local community, with members of the FAS/FAE community, and professionals in the medical, educational, and social service systems. It is this type of interaction which is the focus of symbolic interactionism, which forms the theoretical foundation of grounded theory:

Symbolic interactionism stresses that human behaviour is developed through interaction with others, through continuous processes of negotiation and renegotiation. People construct their own realities from the symbols around them through interaction rather than through a static reaction to symbols. Therefore, individuals are active participants in creating meaning in a situation. (Morse and Field, eds., 1995: 27)

However, since the 1960s "...grounded theory has been elaborated beyond symbolic interactionism and now takes into account the methods and philosophy of phenomenology, linguistic analysis, ethnomethodology and narrative research, and biographical research" (Morse and Johnson, 1991: 4). This research project used some elements of narrative research. The details of this are explained in the Analysis section of this chapter.

Furthermore, according to Annells' (1996) analysis of the postmodern aspects of recent trends in grounded theory, through the use of a conditional matrix the researcher will be able to introduce issues such as class, race, power, and so on into the analysis. The conditional matrix divides the social arena into a series of levels, within which actions and interactions take place. This is conceptualised as a series of concentric circles, beginning at the centre with individual actions, passing through organisational, community, national and international levels of interaction. Strauss and Corbin (1994)

have found that grounded theory method has an openness to contemporary social and intellectual movements, such as various aspects of postmodernism, that enter analytically as conditions into grounded theory studies (Annells, 1996: 276).

Finally,

there are common epistemological underpinnings of feminist theory that are consistent with grounded theory. First, women can be knowers, and their experience is a legitimate source of knowledge. Grounded theory was not developed to give women a voice or to facilitate the development of knowledge for women; however, the investigator through theory development interprets the perspectives and voices of the people studied. (Wuest, 1995: 128)

Grounded theory, then, is compatible with both postmodern and feminist research methods. It is important to establish these connections at this point, for I take the stance that these mothers are the experts on both their children, and their experiences. Although this project examines the lives of five families of children with FAE, including the way parents and siblings interact, the participants are the mothers<sup>1</sup> of these children. The stories are told from their viewpoint. Also, as noted in Chapter Two, the issues which arise from this study can be elucidated through the work of Frank and Kleinman (among others) who take a postmodern approach.

### 3.3 The Research Question

My personal experience with fetal alcohol syndrome began when I had children in my class with FAS,<sup>2</sup> when I was teaching grade two on a reserve in northern Saskatchewan in the early 1990s. I knew relatively little about the syndrome at that time. I did learn, from the resource teacher, that I needed to be patient with these children because they often forget what they have learned and need to be retaught. While I observed some hyperactivity and attention problems, the children listened attentively to stories and wanted to join in most classroom activities. This limited experience showed me the many obstacles these children had to overcome.

When I was asked to investigate and report on a significant health problem in Saskatchewan for a graduate level class in community health and epidemiology, I decided to focus on fetal alcohol syndrome, which had recently been discussed in the media. While researching this project I became aware of many unanswered questions which were well suited to the research methods of anthropology. Specifically, it soon became

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<sup>1</sup>One interview was conducted with John, Debbie's husband. I decided to include his insightful comments in the analysis.

<sup>2</sup>There was a note in their school records that would support an FAS diagnosis. In retrospect, they had all the facial features, small stature, and small head circumference as well as learning difficulties.

apparent that individuals with FAS and FAE were often described apart from their social contexts, in the laboratory or classroom setting. In addition, parents who were raising these children had very little input into the research on, or public perception of these individuals.

I believed that by interviewing parents about the ways in which their children interacted at home, school and in the community, I would be able to discover some insights into the specific difficulties with social interaction which researchers have reported in people with FAS/FAE. I was also interested in the parents' interpretations of their children's behaviour, as compared to clinical descriptions, and such issues as their encounters with physicians, teachers, and other service providers. What advice could they provide to professionals about these children based on their experience as parents, and what could they recommend to improve services?

I undertook a thorough literature search before I began to plan for the interviews. This literature search included six months of monitoring the internet group Faslink, which is a forum for support and information exchange primarily of parents and other caregivers of children with FAS/FAE. Postings on this site were a valuable source of current issues and concerns of parents. While it is important in grounded theory methodology not to fit the data into a preconceived theoretical framework, experts in this research method "recommend that in order to prevent the 'reinvention of the wheel' the student must first do a literature search and then 'bracket' the knowledge (i.e., set it aside) and later in the investigation return to the library to link findings with the work of others" (Morse and Johnson, 1991: 6). Regarding research questions in grounded theory, Wuest states that :

Grounded theory has an emerging design that begins with a broad purpose of determining what is going on within a particular area of interest. Data analysis occurs concurrently with data collection and the specific focus or research question emerges as the analysis proceeds...The researcher does not impose her or his notion of what is most significant. Thus, grounded theory, by allowing the research question to emerge from the data, is well suited to feminist research. (1995: 129, emphasis added)

Information from the literature search is included under the rubric of "data," as well as statements made by the participants in the interviews. From this data I formed the research question, "How does having a child with FAS or FAE affect the way families conduct their day-to-day lives?" Once I had a research question in mind, and had satisfied my thesis committee's requirements for a proposal. I wrote up an application for evaluation of the project by the ethics committee. Once the study was approved by this ethics committee (see Appendix B), my task was to plan a means of contacting parents of children with FAS or FAE.

### 3.4 The Participants: Making Contact

Once my study had been approved by the university ethics committee in November of 1996, my first strategy in contacting participants was to approach a research facility which runs a clinic which serves children with disabilities, a large number having FAS or FAE. Researchers, however, were unable to give me access to their large database of clients, primarily because they were already supporting several other students in their research. This was disappointing, as detailed data are kept on each individual, such as whether they are living with foster, adoptive or biological parents. Therefore, I would have been able to approach a variety of different types of families, with a member of the clinic staff acting as a contact person. However, once the interviews were underway, I learned that close association with this clinic could have been a liability, since parents were unhappy with this clinic's current inability to help them. The children's clinic focuses on testing children, and its primary focus is on providing services to those with multiple handicaps. The children in this study do not fall into this category.

Meanwhile, two of my committee members informed me that they knew of couples who had adopted children with FAS. They agreed to act as contact people and explain the nature of my study. One of these families agreed to participate in the study, and I conducted the initial interview with this participant, Josie, in February of 1997. She indicated that she would be unavailable for further interviews for at least a month after that, and I said that was not a problem, since I would be attempting to contact other participants in the meantime.

As described in Chapter One, Josie's sons are young adults living away from home. While she is still in contact with both of them, they are now living with their girlfriends' families on a reserve, and are no longer her responsibility. According to experienced researchers, Josie was an ideal candidate for the initial interviews, since she was able to describe her entire experience of parenting, after the turmoil of active parenting had passed:

As informants who *are going through* an experience may not have had the time or the energy to *make sense* of the experience, it is recommended that the first informants should be chosen from those who have passed through the experience.. By hearing the entire story from beginning to end from several participants, common patterns or critical incidents will become evident to the investigator. (Morse and Johnson, 1991: 6-7)

Unfortunately, I had only one participant to interview at this point in the research. I did have another mother of adult children, Paula, contact me later in the study, and she was able to look back on her experiences, although she was still apprehensive about her sons' troubled lives.

While I was interviewing Josie, I continued to monitor the Internet group, and I was surprised to find that many of the parents in this group were having the same problems that Josie had experienced a decade earlier. I also read *The Broken Cord* again because Josie pointed out the many parallels between her son Mark and Dorris's son Adam. Also, as people in our relatively small department heard about my study, I had many people coming up to me and telling me stories about children that their parents, aunt and uncle, friends, neighbours or colleagues had adopted or fostered: children who had recently been diagnosed with, or whom they strongly suspected to have FAS or FAE. Many of them had undergone or were currently going through crisis situations. Listening to and reading these stories reinforced my awareness that there are many families who need help, and motivated me to continue searching for participants, and to focus the research on the concerns of the parents rather than my own particular interests.

In this province, 80 percent of identified cases of FAS are of Aboriginal ancestry (Habbick et al., 1996). The majority of these individuals who are children and adolescents are living in adoptive or foster homes (Ibid.).<sup>3</sup> I decided that by focusing my energies on these two groups, adoptive and foster parents, I could reach a large number of families.

Letters of introduction, contact form and a written explanation of the study (Appendices C, D, and F) were sent to the provincial headquarters of the Adoptive Parents Association (SAPA) and the Foster Parents Association, along with an advertisement (Appendix E).<sup>4</sup> The advertisement asked people who were interested in participating in the study to contact me for further information. Therefore, they could remain anonymous unless they decided to participate. This was an important consideration given the potentially stigmatising nature of an FAS/FAE diagnosis, and the need to maintain privacy.

The Foster Parents Association said I should first clear the study with Social Services. Their research and evaluation department took several months to review my proposal, and by the time they had deemed it acceptable I had completed the majority of the interviews. I asked them, however, to publish my letter in their monthly newsletter in August, 1997. I received no responses to this advertisement. I was encouraged, however, by the favourable response which I received from Social Services, who said my research sounded both interesting and worthwhile. SAPA agreed to mail my letter to their membership, and, when I had received no replies after one month, published this letter in their monthly newsletter (Appendix E). I received one response from this mail out, and

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<sup>3</sup> The study by Habbick et al. did not include individuals with FAE. A larger study conducted in Seattle found that about 43 percent of individuals with FAE between the ages of six to adult were living with either adoptive or foster parents (Streissguth et al., 1996: 17-18).

<sup>4</sup> The contact form, Appendix D, was not used by the participating agencies, since they did not have the resources to contact people by telephone.



this person, Susan, was eager to participate in the study after our initial phone conversation. I began interviewing her in May of 1997.

I can only speculate as to why more people did not respond. According to the literature ( e.g., Dorris, 1989, Kleinfeld and Wescott, eds., 1993) there are several possible reasons. Children with FAS and FAE are extremely demanding of time and energy. Many families are struggling to cope and could not possibly spare any time to participate in a research project. There is a stigma attached to FAS and FAE since it is associated with alcoholism, which itself carries a stigma. People, therefore, are reluctant to identify their children as part of a group which society tends to reject. Some parents may not want their children labelled, since teachers and others may impose limited expectations on them. Finally, many parents who are raising or have raised teens and young adults with FAS or FAE may never have received a diagnosis for their children.

Raymond (1997) found it equally difficult to contact participants for her study of the educational needs of children with FAS and FAE. Some of those she did contact were unable to remain in the study due to their hectic lives. Murray (1998), who interviewed adolescent children of alcoholics, states that , “Obtaining participants for the study was a very difficult task ”(p. 128 ). In personal communications with both these researchers, they urged me to be persistent, and not to be afraid of pursuing alternate routes to find participants for the study since these strategies worked for them.

By our third interview, Josie and I had established a level of rapport where I felt comfortable asking her for some suggestions regarding alternate methods of contacting participants. I did not need to ask for her help, however. She asked me how the research was going and when I admitted to her that I had only managed to secure two participants for the study she said, “I’ll make a few phone calls.” About one week later she called me and gave me the names and numbers of three couples who were interested in participating in the project. Paula was long time acquaintance of hers who had been part of a support group which Josie and her husband attended several years ago. Debbie and Eva are close friends and neighbours whom Josie had met recently at a social function completely unrelated to either adoption or FAS. Josie stated that Debbie and Eva were really knowledgeable on the latest research and had been very proactive in trying to get services for their children. She thought they would make very good respondents.

Indeed, all these women were “good respondents,” since they had an intimate knowledge of the subject matter—being a parent of a child with FAE— and were willing and able to describe their experiences eloquently. Hence, they met the criteria for “[t]heoretical sampling [which] dictates that the researcher knows who best to invite to participate, based on the theoretical needs of the study and the knowledge of the participant” (Morse and Field, eds., 1995: 80). These participants were self-selecting, or a “volunteer” or “convenience” sample since they volunteered to be in the study by replying to an advertisement or a request to participate. Since Josie passed the word on to

several other participants, they were contacted by the “snowballing” method.

When using a volunteer sample, as I did, the researcher should use secondary selection. This means that if a particular participant turns out to be inappropriate, this interview is neither transcribed nor analysed but is filed away, and no further interviews are conducted with this person (Morse and Field, eds., 1995: 83). I did not find this necessary. A further safeguard when using this method of participant selection is to use secondary respondents (Ibid.) or secondary data sources such as policy documents or quotes from other studies (Strauss and Corbin, 1990: 52) to verify the data. I used quotes from adoptive parents who testified at the Commons subcommittee hearings on FAS (*Canada* 1992a and 1992b), books and articles written by other parents of children with FAS and FAE (Dorris, 1989; Davis, 1994; and Kleinfeld and Wescott, 1993), information from community consultations and needs assessments (Manitoba Medical Association, 1993; and Tournier, 1994) and quotes from the studies by Stade (1995) and Raymond (1997) both as data sources to be analysed, and as corroborating information to verify the findings.

As explained in Chapter One Debbie, Susan and Eva are raising preteen children with FAE. They continue to face daily challenges. According to Morse and Johnson, they are going through the process of parenting, and should be the second group of respondents questioned:

After discovering the common patterns and critical incidents the next phase in sampling is to find informants who are presently experiencing those various phases in order to confirm or refute emerging hypotheses, to address specific questions, or to expand on certain points. (1991: 6-7)

However, while all the participants shared some issues in common, the social context (the conditional matrix) had shifted considerably in the decade between the adoptions of the oldest and youngest children in this study. The differences between the two groups of parents reflect this change, and were some of the most important findings of the analysis.

### **3.5 Data Collection: The Interviews**

As described in Chapter One, the six participants, five adoptive mothers and one adoptive father are white, second and third generation Canadians, of Eastern European, Scandinavian, and British descent, and are all in their forties and fifties. All have some post-secondary education, from vocational college diplomas to doctoral degrees. Eight children, all of Cree or Saulteaux descent, with diagnosed or probable FAE are discussed in the narratives.

The participants were contacted by telephone. Josie phoned me in response to information about my project which was given to her by one of my committee members. Susan called me in response to my advertisement in the SAPA newsletter. I phoned

Debbie, Eva, and Paula after Josie had informed them about the project, and they had given her permission to give me their phone numbers. I described the project to each of them over the phone, and they all agreed to participate at that time. I explained that I had further written information for them, that I would do my best to maintain their anonymity, that there was a demographic profile to fill out, and consent forms to sign. The demographic profiles were mailed to the parents' homes before the first interview, with a copy of the written information and consent forms. We negotiated a time and place for the first interview, which was at least a week after they had received the written forms.

### **3.5.1 The Interview Process**

At the first interview, after introducing ourselves and giving participants a chance to answer any questions they had about the project, we began by going over the consent forms, and I reminded each participant that they could withdraw from the study at any time. Next, we went through the demographic profile (Appendix H) item by item, first for the parents and then for the children.

The interviews were semi-structured in that I used a list of pertinent topic areas drawn from my literature search. While the researcher should let the interviewees explore topics that they feel are most relevant, it is useful, especially in the earliest interviews to prepare several open-ended questions, to keep the interview focused (Morse and Field, eds., 1995). A sample interview schedule is presented in Appendix K. These questions changed as the interviews proceeded, allowing the participants to bring in topic areas which they thought were important, and discarding items they found irrelevant. This conforms to the procedures of grounded theory methodology, in which questions must change to pursue patterns in the data as they emerge (Strauss and Corbin, 1990).

It helps the interviewees to feel at ease if they are allowed to choose the setting (Morse and Field, eds., 1995). Participants were interviewed in their homes, my home, or their place of work, at times which were most convenient for each individual. Three of the participants (Josie, Eva, and Paula) were interviewed in their homes. Two of the interviews with Josie were held in her office since this was more convenient for both of us. One couple (Debbie and John) asked to be interviewed in my home since one of them had to be at home at all times to care for their twelve-year-old daughter, and they stated that it would be impossible to carry out an interview in their home. Susan, who lives on a farm in a nearby community, was also interviewed in my home when it was convenient for her to come into the city.

The interviews were conducted over the period from February to September of 1997. During this time significant events and changes took place in the lives of the participants and their families which single interviews or a questionnaire would not have captured. Holding more than one interview gives the researcher and participants more time to build rapport: “[m]ultiple interviews are necessary in feminist research to

overcome the problem of participants only providing “public accounts” (Wuest, 1995: 130). Furthermore, “[b]esides building trust that may result in richer and more complete information, multiple interviews allow the participant to be involved in the analysis process” (Ibid.). As will be described below, “[d]ata are analyzed as collected and interpretations clarified in each subsequent interview with the same or different participants” (Wuest, 1995: 131).

Each person was seen an average of four times, and each interview lasted from 30 minutes to one and a half hours. Time spent talking before and after the interviews added about another half hour to each session.

Conversations were tape-recorded and unedited transcripts were returned to participants for correction and comment. I began with an understanding of the sensitive nature of some of the material which we would probably discuss, such as medical histories, and experiences with school or medical personnel. Several measures were taken to maintain confidentiality. The interviews took place in private locations, they were transcribed in my home, and all tapes, and written records and computer disks were stored in my home. Once this project is completed, the tapes will be erased. The information in the demographic profiles and the transcribed interviews was seen only by myself. Code numbers were assigned to each individual, and these were used to identify each interview. For instance, the first interview was labelled as “participant 1, interview 1” on the cassette tape and typewritten transcript. Once the interviews were transcribed, copies were given to each family for critical comment, which was then incorporated into the transcripts. All names were replaced with pseudonyms and identifying information, such as place of residence, was changed before any portion of the text was shown to my supervisor or thesis committee. The names of local organisations and institutions have been changed or deleted in order to conceal the location of the participant families, while provincial and national organisations have been identified. These changes are reflected in the Family Histories presented in Chapter One, and in all quotes appearing in this thesis.

Twenty-one interviews, with six parents of children with Fetal Alcohol Effects (FAE), were conducted over eight months. Five of the six participants were adoptive mothers, one an adoptive father (John, married to Debbie). I had originally requested that both parents take part in individual interviews and this was agreed to by three of the couples, but, later, time and work constraints were given as reasons for the non-participation of each of these husbands. The remaining two husbands did not wish to participate; one because he and his wife had been married for only two years, and the second because he was uncomfortable with being interviewed. All the husbands (according to their wives) demonstrated a real interest in the project by helping fill out the demographic profile, discussing issues brought up in the interviews, and reading the interview transcripts.

### **3.5.2 Fieldnotes**

I made written notes throughout the research process. I kept records of progress of the project, problems I encountered, people I contacted, and ideas and questions that arose. My more personal observations included reflective notes, which were recorded in a notebook, about feelings, and possible ethical dilemmas or prejudices. By making these explicit, it helped me remain aware of any possible bias that could enter the analysis, so as to curb such distortion. I made detailed descriptive notes after each interview session. I included observations about the interview setting, and emotional and behavioural responses of the participant and myself. These notes were written on looseleaf paper and placed in the binder after the matching interview transcript. In some cases, the discussion continued after the tape had been turned off, and I asked permission to use this material. These notes were first handwritten, then typed on to the end of the interview transcript.

### **3.5.3 The Demographic Profile**

The Demographic Profile was an important research instrument in this study. The Demographic Profile (Appendix H) is a standardised form which I adapted from Stade (1995)<sup>5</sup> to document basic demographic information for both the parents and children of each family. Demographic characteristics need not be included unless they are significant within the emerging model (Morse and Field, eds., 1995). In this case, the characteristics of the families as adoptive, with the children and parents being of different ethnicities-- Native Canadian and Euro-Canadian respectively--was fundamentally important to their experiences. Information was recorded for both parents,<sup>6</sup> since the unit of study was the whole family. John, Debbie's husband, was interviewed, and Clive, Larry and Bob participated by being present at some of the interviews, and reading the interview transcripts.

At the first interview with Josie (my first participant) we filled out this form together. This proved to be quite time consuming. For the rest of the participants, I gave them the demographic profile with a copy of the written information and consent forms at least a week before the first interview. I also moved some items from the first interview schedule regarding the children's medical and school histories to the demographic profile form for the parents to fill in. Some of these items were based on questions included on a Research Interest Form posted on the Internet to recruit families of children with FAS/FAE by the Boston School of Medicine (Morse, 1997).

Mothers commented that filling out the form was useful, for it helped them recall

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<sup>5</sup> I also modelled my letter to agencies, written explanation, and consent forms after Stade's examples which are presented as appendices in her thesis.

<sup>6</sup> All wished to participate and signed consent forms except Paula's husband Clive. Clive felt that he did not know enough about the history of the family since he and Paula were only recently married. While he signed the consent form, Larry later decided that he did not want to be interviewed.

specific information about their child and list it systematically. It gave them an idea about some of the questions I would be asking in the interviews, since I explained that this was just a starting point, that we would be discussing this information more fully in the actual interviews along with topics that they could suggest. I encouraged the participants to critique the form to identify additional items, and to suggest alternate terms or ways of categorising some of the information. For instance, Paula commented that there was no section to list addiction problems (although I had provided a space for “health problems”) and this was very important since substance abuse would be “an almost universal problem” in teenagers and young adults with FAE. Debbie said that while she did not think her girls were “mentally retarded” since they have IQs in the 80s (in the normal intelligence range), if you were to define intelligence in terms of social functioning her children would be disabled or “retarded.”

I found this form especially useful in discovering some of the terminology parents use to describe their children. This turned out to be a crucial issue both in a practical sense for the parents, and for the theoretical model which grew out of the analysis. For instance Debbie crossed out the word “delay” in the phrase “developmental delay” and wrote the word “peak” in its place. She explained that “delay” implied that the person would eventually catch up in whatever skill or ability in which they were currently “behind.” The word “peak” on the other hand, indicates that this is the highest level of achievement the child will reach, and it is fruitless trying to push them any further. In discussing the completed forms, I also discovered some of the issues which were of greatest importance to each of the families at that time. It was also a good “ice-breaker” with which to begin the interviews. Since I began the first tape-recorded interview with each participant by going over the demographic profiles, the data contained in them became part of the interview data.

### **3.6 Data Analysis**

The purpose of grounded theory research is to create substantive theory which is illustrated by way of a model which emerges from the data. The important processes, which are identified in the analysis, are linked together in a conceptual model. The model must illustrate which conditions lead to the phenomenon being studied, and the context in which the phenomenon takes place. This context influences the action and interactions (the strategies) of the participants, and these actions lead to consequences.

In each particular model a core category or central phenomenon, is identified, and all the other processes which have been identified, along with their antecedents and consequences, become subcategories of the core category. This core category must be able to integrate all the other categories, to link them together. The dynamic model which results from this type of research illustrates how the experience changes over time for the individuals undergoing it, and how they modify their strategies to accommodate evolving

conditions. The theory must also account for variation, and integrate the wider conditions (for instance social and economic) that affect the phenomenon under study, into its explanatory framework (Strauss and Corbin, 1990). The model which emerged from the data in this research project will be introduced at the end of this chapter, illustrated in Chapters Four through Seven, and linked with comparable theories derived from my literature search in Chapter Eight. Here, I will describe the major steps in the analysis of the interviews, which led to the development of the model.<sup>7</sup>

### 3.6.1 Transcription of the Interviews

Preliminary data analysis took place concurrently with data collection, so, in fact, the phase of data collection overlapped the period of data analysis. After I sorted the data to search for and interpret patterns in the participant's narratives, I used the data analysis procedure of constant comparative analysis. The interviews were transcribed by me, immediately following each interview. Since this work was time consuming I scheduled no more than two interviews in one week, and interviews with each person were held a minimum of one week apart. The advantage of transcribing the interviews myself, rather than hiring someone else to do this work, was that since I had been present at the interviews, I was able to recall words and phrases that may have been somewhat unclear on the tape. I remembered each interview as a whole, and was able to recall the topics and incidents we discussed. The fieldnotes were also helpful in filling in the contextual details of each interview.

The participants often took pauses to collect their thoughts, to choose the best example to illustrate a point, to recall an incident, and to reflect on what they had said.

According to DeVault (1990), interviewers must learn to,

‘develop ways of listening around and beyond words’ by attending to the groping for words, the hesitations, and even the ‘you knows’ to round out what might be ‘incompletely said.’ (pp. 101, from Wuest, 1995: 133)

This includes the paradoxical, the marginal and the contradictory (Wuest, 1995). Indeed, by noting the intensity of feeling and the seeming contradictions in the mothers' stories, I was analysing the data, for these became important elements in the conceptual scheme.

I transcribed the interviews verbatim using a Claris Works word processing program. Morse and Field (1995) state that “[d]uring the transcription process, it is

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<sup>7</sup> There is insufficient room here to go into minute detail. The reader is referred to *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, 1990, Anselm Strauss and Juliet Corbin: Sage Publications, Newbury Park CA, and *Qualitative Research Methods for Health Professionals*, Second Edition, 1995, Janice Morse and Peggy Ann Field eds.: Sage Publications, Thousand Oaks, CA.

important that all of the interview material be transcribed verbatim... [t]hese directives are important for maintaining the integrity of the data during the analysis phase (because it enables the researcher to continue to 'hear' the interview)..." (p. 175). Mishler (1986) states that the most important rule to follow when transcribing interviews is to be consistent in the conventions one uses to indicate such things as pauses in speech. Below I will discuss the punctuation and other means used in this thesis to assist the reader to better "hear" the interviews.

I used my judgement regarding the normal conventions of speech when punctuating the text. Mishler (1986) indicates the need to carefully note who is speaking, and to show when speech overlaps when one person interrupts another. I used the first initial of the speaker and a colon before each sentence or paragraph to show who is speaking. When one person's speech is interrupted by another's I indicate it by the following means:

A: Are you going to take the highway into town today or]

B: ...Oh not the highway, it'll be far too busy.

Thus, the section of text which overlaps on the page mirrors the overlapping spoken words. I followed the suggestions of Morse and Field (1995) to use square brackets within the text to enclose descriptions of emotional states, e.g. [laughing] or explanations for interruptions in the interview, e.g. [Child enters room]. A pause is indicated by [pause], and a longer silence by [long pause].

Regarding the use of quotation marks:

Qualitative researchers use quotation marks frequently in their writing to draw the reader's attention when a common word is being used uncommonly. The quotation marks may indicate that the word was used deliberately, denote that the word is being used as it is used by the participants or denote the special meaning intended. (Morse and Field, eds., 1995: 174)

For example, the word crazy was used by participants not to mean "insane," but to indicate the implication that they are not credible, that they are imagining things, they do not know what they are talking about, or that they are hysterical mothers. In Chapter Six, I explain that :

[t]he great imbalance of power in these initial relationships between mothers and professionals was evident in several recurrent themes: professionals dismissing the mothers' perspectives, practitioners blaming parents for their children's behaviour; and mothers feeling like they're on an emotional rollercoaster. The cumulative impact of these encounters leaves mothers feeling that they have not been validated, are inadequate, and even "crazy." (p. 4)

Quotes within quotes are found frequently throughout the narratives, as mothers



often reconstructed conversations in order to set the scene. In the following passage, Susan talks about her son's first day of kindergarten.

Susan:

One of the other mums who was with me that morning said, 'Oh aren't you opening the blinds?' And she said, 'Oh no I find they're too much of a distraction.' And I thought, 'Oh my gracious here we are in kindergarten, and we might be distracted by the birds outside or something!'

Throughout this thesis italics are used to indicate the processes, stages, and phases of the model. For instance:

The focus in this chapter is on the process which mothers undergo in *becoming advocates*. There are two interacting strategies which mothers use in order to secure both the knowledge and social support which they say are necessary to enable them do the work of advocacy. I have labelled these strategies *navigating the systems* and *creating the FAS/FAE community*. (Chapter Six, p. 130)

Underlining is used to emphasise words, both in quotations and in the description and analysis. For instance, Susan, in the following passage, said the underlined words both with emotion and raised volume.

Susan:

His cumulative file says that he had premeditated --if you can picture that-- assaultive behaviour. 'Premeditated' would never be a word in my whole life that I would use for James. I mean these are instant children [ie. they act without thinking].

After the interviews were transcribed onto my computer, I printed several hard copies for the analysis. I initially made three hard copies of each interview, two for myself and one for each participant. One of my copies was three-hole punched and put in a binder, one was filed away, and the participant's copy was sent to them for comment and correction. One copy of each interview was kept on my hard drive, and one kept as backup on a floppy disk.

### **3.6.2 Constant Comparative Analysis**

After each of the first few interviews, I made two readings of the transcribed text. I began by reading the written copy of each transcript through completely, highlighting

words and phrases that stood out and making marginal notes regarding material which needed further explanation or clarification, and research leads to be pursued. These comments and observations were transferred to a notebook, where they were expanded into descriptive summaries, and notes. From these I drew up a list of questions for the next interviews, making note of the statement from the last interview which led to the particular question. For example, in one interview I asked Josie if Mark had any learning disabilities. She replied, “He had learning difficulties, we didn't call them disabilities.” She then went on describe his particular learning problems. At the time I had assumed that they didn't use the term “disabilities” because it could be stigmatizing. However, I decided to check this information, and at a later interview I read her reply and my interpretation of it. She corrected me:

Josie:

Well I would say that Mark is certainly disabled in his learning. I guess I think of learning disabilities as those that are categorised. I guess dyslexia is the only one that I have a name for. I don't know if his has got a name. That's probably why I didn't [pause] I'm somewhat hesitant to call it a learning disability.

Not only did I avoid misinterpreting her statements, but the issues of categorising and naming concepts in order to make them “real” became crucial components of the theoretical model. This is an example of interpretations being clarified in a subsequent interview with a participant. It reveals the value of multiple interviews which give participants the opportunity to be involved in the analysis process.

The second reading was done on the computer. I coded sentences and paragraphs into different topic areas which were common to the interviews. Some of these initial codes included the diagnosis, professionals, experts, addictions, learning at home and school, the biological family, and help and support.

As suggested by Strauss and Corbin (1990) the entire text of the first few interviews was coded and sorted since, at this early stage, the researcher cannot be sure which material is either important or relevant. Since, “... there is a responsive interaction between the collection of data and the analysis, with the interviews directing the coding and vice versa” (Morse and Johnson, 1991: 7), as the interviews proceeded new codes were created, some categories were combined and renamed, and some categories were broken down into several different categories and given new codes. It is important to note here that “[i]n grounded theory ‘in vivo’ codes are used, that is rather than using known concepts or variable labels as codes (such as ‘social support’ or ‘coping’) labels are taken directly from the interview using the language that the informants themselves use...(Ibid.). Conventional concepts, however can be used as codes, as long as the

definition is made very explicit to avoid misunderstanding (Strauss and Corbin, 1990). An example of a code taken from the participant's own language is "converting people" which Debbie coined but the other participants also described. When mothers convert people they are able to target sympathetic individuals and to advise them of the correct way of approaching their children. This strategy of *converting people* is discussed in Chapter Six.

To discover the stages and the characteristics of each stage, I used the methods of memoing and diagramming. Memos include "notes, insights, comparisons, summaries and questions" (Morse and Johnson, 1991: 7). Through these processes, the analysis becomes more abstract as the model is developed. An example of a memo can be found in Figure 3.

In Fig. 3 on the following page I have indicated some central issues, and have posed three questions (Q#1, Q#2 and Q#3). More questions would arise than the three posed here as example of leads to future research. This research could include formulating questions for future interviews, going back to the literature, or returning to the interview transcripts for answers. In this case, I had already completed the interviews.

To answer question #1, it was necessary to review the interviews and search for statements which revealed Josie and Paula's attitudes toward professionals. They had made it clear that they respected the authority and expertise of professionals, especially doctors. They felt that they had neither the confidence nor the knowledge to question their authority. Both expressed the view that, to paraphrase, "back then, that's just the way things were." It was necessary at this point to search the literature for analyses of "the way things were," specifically, anthropological analyses of the culture of biomedicine. To gauge how the situation has changed, Josie's and Paula's interactions with professionals were compared with those of Eva, Susan and Debbie.

In response to question #2, the particular circumstances of Paula and Josie must be examined in detail in addition to the changes in their attitudes brought about by changes in cultural values regarding interactions between doctors and their patients, which form part of the conditional matrix.

Dec. 4, 1997

DECISION MAKING RE. TYPES OF TREATMENT\*

\*(teaching strategies, behaviour management, medical treatments)

Parents of Young Adults

J. and P., much like M. Dorris were willing to "try anything" for their children, which included counseling for themselves and their children, and parenting classes

Their stories tell of a search for sympathetic and knowledgeable professionals to help them.

While they disagreed with them on certain points sometimes, they deferred to the knowledge and expertise of professionals (counsellors, doctors, teachers).

In the past.

Now: P says there is need to change the justice system

J says knowing what she knows now, she would do things differently

Q #1 -What was different in the past?(conditional matrix/history)

Q #2 -What has led Josie and Paula to change their approach?

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Parents of children age 9-12

E D and S take a different approach

They are proactive regarding their children.

They "make their presence known" in the school

-E and S volunteer in the classroom

-D negotiates with the principal, gives resources and ideas to teachers

They negotiate with doctors, and are willing to make compromises as long as the benefits outweigh the risks of a particular treatment for their child.

They never take their advice at face value.

They will not "try anything" if they think it probably won't work for their child.

(may let down their guard in times of crisis: eg. Debbie using Ritalin during Kate's puberty)

Teaching strategies, treatments, behaviour management techniques are carefully researched. Q#3 (How?)

There is a gradual learning process. It is described in terms of then\now

Reading The Broken Cord was unanimously described as a "starting point" on a journey, quest , process of learning and discovery that leads to empowerment. [They place themselves on different points along the road]

To answer question #3, I first performed a content analysis of all the incidents of professionals suggesting or prescribing (applying) a treatment or teaching strategy, noting the outcomes of that treatment, and the responses of the mothers to this outcome. Next, I did a content analysis of incidents in which parents exchanged information about a particular professional they had encountered, or a treatment their child had received (noting its outcome), or that they had heard about. Finally, I noted the similarities and differences between them.

As the analysis became more focused on a few conceptual categories I was able to combine the two analytic processes described above. The theoretical memos and conceptual maps (flow charts, lists, and diagrams) were written in my notebook, and, using the computer, appropriate quotes in support of these emerging patterns were cut and pasted from the interview texts to files with titles corresponding to each stage or category. For instance, files were created with titles such as Paradox, The Systems, Information Sharing, and The Creation of the Family.

As the core category, *redefining parenting*, was defined, I had to examine each of the major and minor categories and specify their relationship to each other and the core category. My "...final step [in the analysis was] to identify the linkages between the categories by comparing and contrasting the conditions and consequences of the relationship between the concepts" (Morse and Johnson, 1991: 7-8).

### **3.6.3 Summary of the Conceptual Model: Redefining Parenting**

*Redefining Parenting* describes the process in which mothers of children with FAE discard their previous conceptions and methods of parenting, and learn to accept their role as parents of special needs children, with all its challenges. Thus, they are *redefining parenting*. There are two major sub-categories: *the evolving family*, as it passes through a series of stages over time; and *becoming advocates* in which the mothers' identities are transformed as they travel on their journey to understanding their children's disability and meeting their needs. A diagram of this model appears on the following page.

The careful use of language or discourse is important to these mothers. The discourses on disability and, to a lesser degree, race, adoption, and alcoholism, which are circulating in society have a direct impact on their lives. They carefully crafted narratives to describe their experiences to me, so that I could present them to a wider audience in this thesis. Furthermore, in their day-to-day lives, throughout the stages of *the evolving family*, they use language for several different purposes.

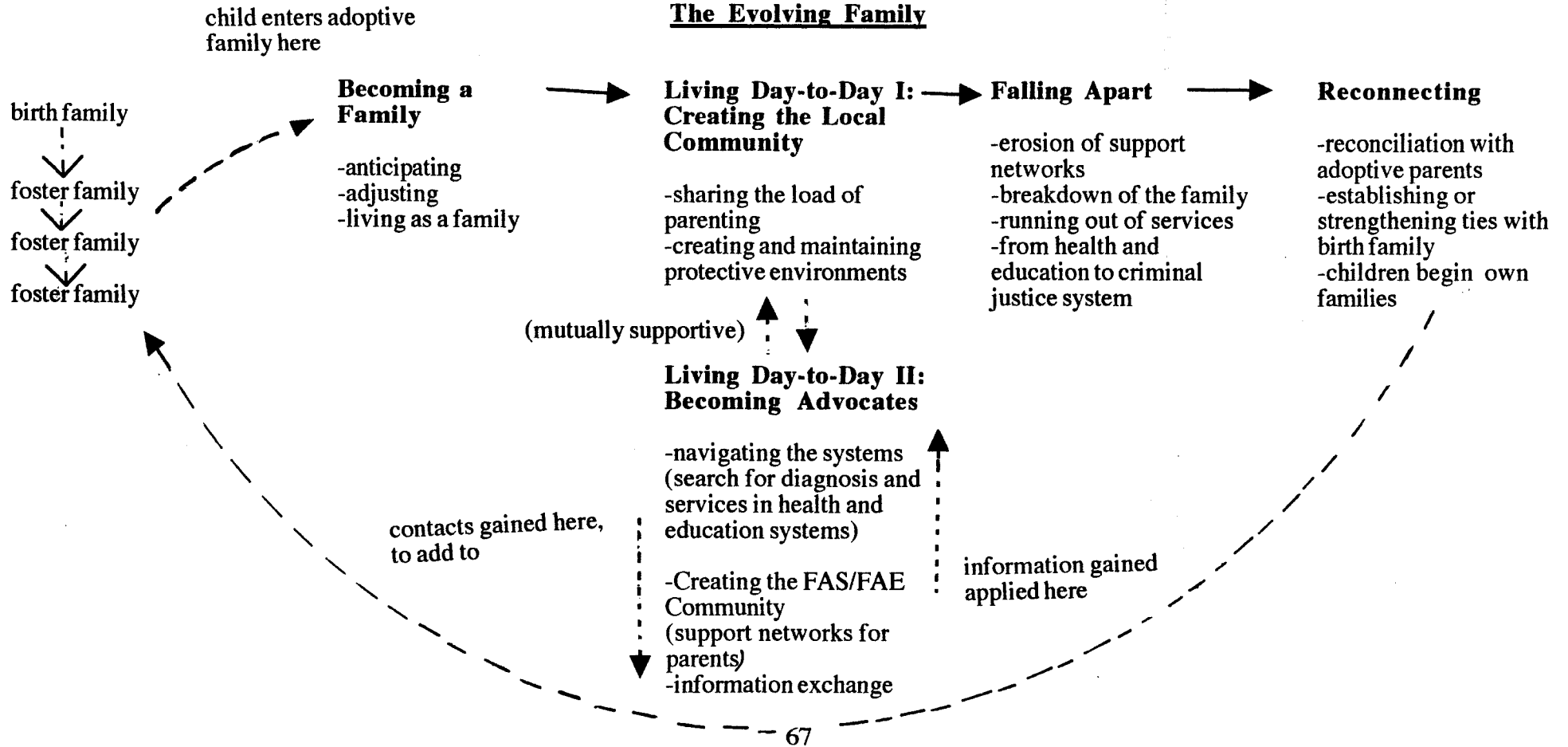
Mitchell and Winslade (1997) contend that both a developmental systems model and a narrative approach are useful in working with families of people with disabilities. I see aspects of both in the "grounded theory" I have constructed:

In brief, a developmental systems model argues that the planning, management and evaluation of services for persons

Fig. 3.2

REDEFINING PARENTING

The Evolving Family



with disabilities and their families must be responsive to the changing developmental needs of the person with a disability. Such a system should be developed with reference to the evolving relational politics of their families and their social contexts at various stages of the person's life story. A narrative model argues that such services should take account of the social location of the person(s) affected by disability, particularly the influence of the discourses about disability that inform these social contexts. (Mitchell and Winslade, 1997: 151)

The parents in this study adopted children with hidden disabilities, whose severity and cause did not become apparent until several years after the adoption. While the medical term for their children's condition is FAE, the parents characterise them as "socially disabled" because they have difficulty establishing and maintaining satisfying social relationships, which is profoundly disabling in human society.

The story begins as the couples await their adopted children. They are full of anticipation of a happy life together as a "real" family. When the children arrive, they have minor health and developmental problems which the parents attribute to their impoverished background. As the children gradually improve, the families enjoy a few years of stability. When children are slow to "bond" (Tim, James, Kate, Mark) the mothers become frustrated with themselves and the children. This causes extra stress for these mothers and leaves them feeling exhausted. It introduces an additional element of tension into family interactions. All the mothers (except Susan) felt some guilt and inadequacy about their mothering ability at that time. Susan had successfully raised two children to their teens when James was adopted, and she approached the task of raising him as just more of a challenge. All three children eventually bonded with the families and remained with their parents for over ten years.

Over time, by gathering data, parents discover their child is different. They adapt their parenting to the special needs of the child. Before they have the child diagnosed with FAE, parents are aware that their child has problems, and will try one thing after another in an attempt to remedy these difficulties. This is a frustrating time for parents, who often blame themselves for their children's difficulties, and are criticised by others. They become angry at the children for their behaviour, and conflict may develop between spouses over the best way to deal with the child. Parents lose confidence in themselves, and allow professionals to take the lead.

Once they learn about FAE, and decide that their child fits its characteristics (the "unofficial" diagnosis), parents are given answers to their questions and a focus for their action. They describe this as a revelation, when a previously puzzling situation became clear. The source of this crucial information was the book *The Broken Cord* (Dorris, 1989) for everyone but Debbie. She learned about FAS/FAE at a workshop, but also heard about *The Broken Cord* (1989) at this workshop, and read it soon after. The next

step is to seek an “official” or medical diagnosis.

As parents seek a diagnosis and go on to seek services for their children, they interact with individuals in the various “systems” such as medicine and education. They soon discover that these systems are large bureaucracies, each with its own rules and language. After several unsuccessful attempts to obtain funding or services through the official routes, mothers decide to take matters into their own hands. They begin the process of *becoming advocates*. They learn the language and rules of each system until they are able to manipulate those systems (*playing the game*).

As parents meet other parents of affected children through support groups, conferences, and workshops they band together to exchange information and support each other in their advocacy efforts. Helpful professionals are drawn into this group. This process is *creating the FAS/FAE community*.

Equally important is the work mothers do to build a network of social support for their children, which will enable them to learn and practice social and communication skills, and stay connected, so they do not become further marginalised. This is *creating the local community*.

The special nature of these children leads to an idiosyncratic socialisation process, hence the core category or central phenomenon, *redefining parenting*. A very specific type of parenting develops which requires added tasks like intensive advocacy work, and tight supervision of even teenaged children.

This leads to parents being criticised, both for their child’s behaviour, and for the way they manage their children. Parents themselves may feel uncomfortable in the role, because it goes against the way most parent-child relationships evolve. Communicating with other parents in similar circumstances (the FAS/FAE community) validates both their feelings and actions, and gives them the strength to continue.

In the case of Paula and Josie, they did not receive an official diagnosis for their sons. Also, they did not learn about FAS/FAE until the boys were in their teens. While they belonged to a support group, they did not have their suspicions about FAS/FAE validated by any professionals. This is most likely a consequence of the lack of awareness about FAE even in the 1980s. This led to a prolonged period of confusion and frustration, of blaming themselves and their children for the children’s behaviour. In Josie’s case she continued to search for ways to help her son. Paula tended to minimise Jason’s problems, until they escalated to a point where he had to leave home. Again, because she had no guidelines on how to manage possible behaviour problems, she was unprepared when Brad’s life began to fall apart. It is only recently that these mothers have, in retrospect, been able to make sense of their experiences, and to put their sons’ difficulties in the context of other teens and adults with FAE.



### **3.6.4 The Evolving Family**

*The evolving family* describes the process of development which the families undergo as they go through time. The stages are *becoming a family, living day-to-day, falling apart and reconnecting*. They provide the context for *becoming advocates*.

#### **3.6.4.1 Becoming a Family<sup>8</sup>**

*Becoming a family* is the first process which parents undergo. There are three stages in this process: *anticipating, adjusting, and living as a family*. *Anticipating* covers the time period from the decision to adopt to the arrival of the child. The parents and children develop relationships during the process of *adjusting*. They begin to feel that they are members of a family, each with their own roles. *Living as a family* entails consciously acting like a family, and partaking in activities together. It is important that they publicly display their status as a family with all the rights and obligations of a biological family.

#### **3.6.4.2 Living Day-to-Day 1: Creating the Local Community**

The major process outlined here is *creating the local community* which is a support system for the child. The “local community” in this thesis has a specific meaning. As opposed to its usual meaning of a geographically bounded neighbourhood, and the individuals who reside there, it is a social network of caring adults who become role models: coaches and instructors, teachers, neighbours, and same-age peers constitute the local community. The sub-processes of *creating the local community* are *sharing the load of parenting, and creating and maintaining protective environments*. *Sharing the load of parenting* has two strategies: *communicating and cooperating, and spelling each other off*. *Creating and maintaining protective environments* entails four strategies: *establishing a peer group, finding role models, structuring the child’s time, and monitoring the child’s activities*.

#### **3.6.4.3 Living Day-to-Day II: Becoming Advocates**

The focus in this chapter is on the process which mothers undergo in *becoming advocates*. There are two interacting strategies which mothers use in order to secure both the knowledge and social support<sup>9</sup> which are necessary to become advocates. I have called these strategies *navigating the systems* and *creating the FAS/FAE community*.

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<sup>8</sup> Chapter Four, *Becoming a Family*, includes a discussion of adoption policies and procedures in Saskatchewan from the mid 1960s to the late 1980s, and the larger social forces which helped shape these policies.

<sup>9</sup> Social support can include information and advice, help with caregiving, or empathy. It can be provided by friendship or kin networks, formal service providers, or support groups (Greenberg et al., 1997). The mothers in this study tended to discuss knowledge or “information” and “help” or support separately, but stressed their interdependence.

While *navigating the systems* parents learn how to find their way around the complex bureaucracies of the health care, education, social service, and justice systems. They search primarily for a diagnosis, services, and treatments but also make useful contacts which may become part of the FAS/FAE community which is the support network parents create for themselves. Furthermore, parents become more confident during their quest.

*Creating the FAS/FAE community* is the way parents set up support networks for themselves. The main goal is to establish emotional and practical support, but information exchange occurs among community members which they use to negotiate the bureaucracies listed above. Parents begin by asking for information and advice from professionals, but soon realise that many are unable or unwilling to help them.. As a consequence of receiving inadequate services for their their children, and the lack of information from professionals, parents look for the support of others in the same situation as themselves, and at this point become part of the FAS/FAE community.

In their contact with the research community and other parents whose children are older than their own, parents come to realise that teenagers and adults with FAE often drop out of school early, become addicted to drugs and alcohol, and suffer from depression and more serious mental illnesses. They have trouble holding down jobs, and lack the life- and social skills to live independently. In *anticipating the future*, parents project these possible futures onto their children, They, however, have some hope that things may be different for these younger children who were diagnosed earlier (except for Cameron, who was diagnosed at 11), and have benefited from strong advocacy from their mothers in the school and health care systems.

#### **3.6.4.4 Falling Apart**

By their children's early adolescence there is growing conflict between parents and their children. The mothers' greatest fear involves the child leaving home. While parents urgently need respite, the only option is usually foster care. Parents do not trust the social service system's ability to safely and adequately care for their children. They say that they will be "lost to the system." Parents have made a commitment to raise this child to adulthood; if they had to give up now they would feel they had betrayed them. The term used by social workers to describe a terminated adoption, "adoption breakdown" (Triseliotis et al., 1997) evokes a picture of dysfunction, failure and defeat (McCreight, 1997; Bagley, Young and Scully, 1993)

This period is characterised by encounters with the justice system, which in some cases lead to incarceration, drug and alcohol abuse, and life as a street kid. Teens with FAE are very vulnerable to harm or premature death. Parents may become victims of crime or verbal and physical abuse from their own children or their friends. Parents still require their community supports, including counselling, in order to prevent a complete breakdown of the family, to maintain their mental health, and to make sense of their lives.

If children and parents survive this period intact, there is some hope that as adults they can establish a satisfying lifestyle, although the children will require some level of support and supervision.

#### **3.6.4.5 Reconnecting**

By this stage the adolescent or young adult children are living apart from their parents, and may have started families of their own. Parents are no longer held responsible for their children's actions by society, and life is no longer a continual round of crisis management. Parents refer to this time as a period when "things had settled down." In the case of those parents whose children were not diagnosed until their adolescence or adulthood, they must now come to terms with the fact that their children will never live up to their original expectations. They must grieve for the loss of the son or daughter that will never be, and accept the children as they are. New expectations must be established that are more compatible with "the way things are" rather than speculating on "what could be." For the parents with younger children in this study, this realization occurred within a few years of the diagnosis. While the future was still uncertain, they were able to describe a hopeful future for their children, which included the possibility of living with their parents for at least part of their adulthood. For mothers *reconnecting* is a period of introspection, of letting go of guilt, and of reclaiming their lives. It is a time of healing, of reestablishing fractured relationships on new terms.

#### **3.7 Variations in Technique: The Narratives**

During unstructured and semi-structured interviews, "[p]articipants usually tell stories sequentially, from the beginning to the end. This makes them valuable sources of information in grounded theory, since it is important to understand the sequencing of events to delineate the process" (Morse and Field, eds., 1995: 92). I have kept these stories intact, summarising them in "The Family Histories" in Chapter One. Also, by labeling the quotes with their pseudonyms, I have allowed the reader to interpret these statements in the context of each family's story. I undertook this exercise after repeated assertions by the mothers in my study that they found stories about other families to be the most useful information they had encountered. They urged me to present the findings of this study in the form of stories that other families could relate to, as far as the conventions of an academic thesis would allow. This reconstruction of the narratives is a departure from, or rather an extension of, the grounded theory method as described by Strauss and Corbin (1990). However, many researchers successfully combine other methods with grounded theory. I have followed the guidelines provided by Leininger (1994). She states that,

[o]ne should not mix research methods across qualitative and quantitative paradigms, but one can mix methods within each

paradigm. If more than one method is used, a reason should be given for its use, and a full explanation of how each method was used. (p.101)

Since grounded theory and narrative research are both qualitative approaches it is acceptable to combine them. Specifically, since the narrative follows these families from their inception to the present, in a broad social context, this research project contains elements of life history:

As a narrative, life history is the stories of people's lives but it is the connection of one's life events to social events that distinguishes life history from other forms of narrative. Life is seen as being lived in a time, place, and under particular social circumstances (i.e. triangulated into history) rather than a simple collection of events. (Wason-Ellam, 1999: 7)

Finally, a study is not complete, and the results not truly "grounded" until findings have been

verified both with participants and similar findings in related literature. The entire model or theory should be presented to the participants, and their feedback incorporated into the model itself or at least accounted for in the final written presentation. (Morse and Field, eds., 1995: 142)

Just as the interview transcripts were given to each participant for correction and critical comment, a copy of their own Family History was given to each family for feedback. Minor corrections were noted by the participants, and I made these changes in the final versions. They were also given a copy of the Introduction which included a description of the theoretical model. I asked them to make written comments on this model if they felt it in any way did not reflect their experience, or if they found anything inappropriate or surprising. These comments would then be incorporated into the final version of the thesis. I initially mailed a copy of the Family Histories and introduction to each family. Participants contacted me by phone, email, or mail to give me their feedback on both the Family Histories and the theoretical model. I phoned those who had not replied after a three week period. Susan was the only person who felt compelled to comment on the model, and her insightful reflections on the process of *becoming advocates* are presented in Chapter Six.

### **3.8 Summary**

This chapter has discussed the methodology used in this research project from its inception to the writing of the thesis. It included a discussion of grounded theory which provides the conceptual framework for the study, the analysis process, variation from the

typical grounded theory methodology, and, finally, the writing process which followed. Chapter Four will describe the process of *Becoming a Family*. It is the first of a series of four chapters which discuss the research findings.

## Chapter Four: Becoming a Family

### 4.1 Introduction

This chapter describes the first process which parents undergo, *becoming a family*, which has three stages: *anticipating, adjusting, and living as a family*. *Anticipating* encompasses the period of time from the decision to adopt to the arrival of the child. This section includes a discussion of adoption policies and procedures in Saskatchewan from the mid 1960s to the late 1980s, and the larger social forces which helped shape these policies. *Adjusting* is the process by which parents and children develop a relationship, and come to feel that they are members of a family. *Living as a family* means consciously acting like a family, partaking in activities as a family, and demonstrating the group's status as a family with all the rights and obligations of a biological family.

### 4.2 Anticipating

*Anticipating* encompasses the period of time from the decision to adopt to the arrival of the child. The average length of time required for this process was two years. It is a time of preparation for parenting, which includes careful screening by adoption services, preparatory classes, and information gathering from friends, family and other adoptive parents.

All but one set of parents in the study had no natural children of their own. Their expectations about parenting and what a family should be like were influenced by observing friends and family members who had children, and their own experiences as members of a family, in addition to the formal training provided by Social Services and the adoptive parents association.

This was an exciting time of eager anticipation when anything seemed possible. Eva reported that her elation was tempered by the negative attitudes of a few friends and family members to their impending adoption of a Native child. These comments reflect both endemic racism in our society and the negative outcomes of some transracial adoptions. All the participants, however, emphasised the overwhelming support and encouragement which they received from family, friends, and members of the adoptive parents association.

Before describing the experiences of these families, an outline of adoption policy in Saskatchewan through the 1970s and 1980s, and some of the larger forces shaping this policy must be drawn. Terms used by the participants such as "REACH" and "special

adoptions” will be defined, and this outline will trace the factors which led these particular people, and many others like them, to adopt Native children in this province at a particular time in history.

#### 4.2.1 Adoption in Saskatchewan

According to *Social Services Annual Reports* (1988) there are currently seven types of adoption in Saskatchewan: 1) Infant Ward Adoptions; 2) Special Adoptions (formerly REACH); 3) Assisted Adoptions, which became effective November 1, 1987, where children identified with specific serious illnesses or disabilities are eligible for maintenance assistance, special services and extended health coverage when adopted into a family); 4) International Adoptions; 5) Step Parent Adoptions; 6) Independent and Third Party Adoptions (formerly “private adoptions”); and 7) Licensed Agency Adoptions, “Under a one year pilot project, Christian Counselling Services, ...undertook to demonstrate open adoption and non-governmental adoption agency services “ (p. 5). Social services facilitates all but the Licensed Agency Adoptions.

Historically in Saskatchewan, as elsewhere, there has been a trend toward specialisation in adoptions. While there are now seven types of adoption, back in the mid 1960s there was simply either “adoption” or “foster care,” with newborns (three months and under)<sup>1</sup> being adopted and the majority of older children remaining in care. The first type were seen as “easy to place”, and the second as “hard to place” (Planning and Evaluation, 1980: 20).

According to Triseliotis et al. (1997), the reluctance of agencies to place older children for adoption can be traced to psychological research which was conducted in the early 1950s on the detrimental effects of separation and loss on children’s mental health. The common belief held at that time was that children over the age of two were unable to form emotional attachments with their adoptive parents. This will be discussed in *adjusting*. Furthermore, by adopting infants, parents are able to replicate the experience of natural parenthood as closely as possible. For now, it is important to discuss the change in attitude which occurred in the late 1960s towards these children which led to the “permanency movement.”

Studies which examine the well-being of children at certain ages after adoption are known as “outcome studies.” By the late 1960s research and experience were beginning to indicate that multiple foster placements for many children were extremely harmful. On the other hand, some outcome studies indicated that if these children were adopted, there was a good chance that they could overcome the effects of their earlier experiences (Kadushin, 1970). Bagley, Young and Scully (1993) point out that Kadushin’s (1970)

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<sup>1</sup> In the *Social Services Annual Reports*, Saskatchewan, statistics on infant adoptions are inconsistent, with “infant” first defined as zero to three months, then zero to six months. In later years, children from zero to five years are grouped together.

study, which was very influential, included only 91 subjects who were all white, healthy, and of normal intelligence. However, later more extensive studies have corroborated these findings (Hodges and Tizard, 1989 and Bohman and Sigvardsson, 1990 from Bagley, Young and Scully 1993: 27).

As Triseliotis et al. (1997) explain, the permanency movement of the 1970s, based largely on these outcome studies showing that older children could be successfully adopted, resulted in a shift in adoption policies to promote adoption of previously “hard to place” children. The definition of a “hard to place” or “special needs” child was one who is over three months old, of a minority or mixed race, a part of a sibling group needing adoption, with a physical or learning handicap or chronic medical condition (*Social Services Annual Reports*, 1972: 29) This definition has remained largely unchanged over the years, except for the age of the children; with fewer children available for adoption each year it is now less challenging to find homes for children under five. In Saskatchewan during the 1970s and 1980s, many of these “hard to place” children were of Native origin.

Following this trend, Saskatchewan Social Services began to place as many children as possible into permanent adoptive homes where these children could find stability. One initiative which resulted from this new policy was the Adopt Indian and Metis program (AIM). In 1967 the AIM program was established in Saskatchewan to encourage the adoption of Indian and Metis children (Department of Welfare, 1969). Through television and newspaper advertisements, and slide presentations to community groups, the need for adoptive homes for Native children was made known. Part of the strategy for recruiting adoptive parents was removing several perceived barriers to adoption.

Adoption was seen as a lengthy and difficult process (Ibid.). Traditionally, parents applied to adopt, were placed on a waiting list, and a year elapsed before the homestudy was begun and the child placed with the family. The adoption homestudy prepares all adoption applicants for placement. It consists of a series of interviews and meetings designed to assess the applicants and prepare them for the role of parenting an adopted child (*Social Services Annual Reports*, 1981: 7). The AIM program reduced the “time barrier” by responding quickly to applicants, and shortening the time of homestudies to four or five months in most cases. Furthermore,

[t]he AIM viewpoint toward potential placements was also different. To AIM, each adoption inquiry represented a valued resource for some child. The homestudy was looked on as a social exploration designed to screen in rather than screen out a potential home, a break from the traditional agency approach merely to approve or reject an application. (Department of Welfare, 1969: 13)



The program was declared a success, with 46 Indian and Metis children being adopted by the end of 1967, compared to only 16 being placed the previous year. Furthermore, “[h]alf of these children were over two years of age and not normally considered adoptable because of the lack of community interest and resources for them” (*Social Services Annual Reports*, 1968: 32). There were also three groups of siblings adopted, another hard to place category of children.

The success of the AIM program led to its expansion in 1971 to include all special needs children. Renamed “The Aim Centre Program,” this program gradually shifted the main focus of its advertising away from Native children to older children and those with disabilities, although Native children continued to be placed through this program and REACH.

In 1975 the Aim Centre Program became REACH or Resources for the Adoption of Children and carried on the same mandate. By the end of the 1970s a concerted effort was made to place Native children with Native families (*Social Services Annual Reports*, 1971, 1975, and 1980). However, these efforts were not very successful:

Current practices are to place children with parents of the same race whenever possible. Children are placed trans-racially only when a suitable adoptive home with parents of the same race is unavailable. This practice is based on the belief that every effort should be made to ease the child’s adjustment. In this case, race is considered an additional barrier to easy adjustment. In addition, there is considerable support for the idea, (most notably among native organizations) that a native child’s overall well being is better served by adoption into a native family.

Unfortunately, there are often more children of Indian or Metis origin seeking adoption than native families waiting to adopt. In Saskatchewan, an estimated 26% of all adoptions involve trans-racial placements, primarily the placement of Indian and Metis children with parents of Caucasian origin. Only 9% of the adoptions involve same race placements of native children with native families. (Planning and Evaluation, 1980: 79)

In 1984 the Federation of Saskatchewan Indian Nations (FSIN) entered into an agreement with Social Services to begin providing adoption and foster care services for status Indian children (*Social Services Annual Reports*, 1985). Their objective was to develop foster and adoptive homes for these children, either with their extended family or with other families in their home communities. The legislation which gives Social Services the power to hand over control of child welfare to other agencies and Band Councils, is the Child and Family Services Act, Saskatchewan (1989-90). Furthermore, when a child who is taken into protective custody is Native, treaty status and appears on the band list, the chief or chief’s designate must be notified of the protection order, and their recommendations

regarding the best placement of the child will be taken into consideration. Family review panels consisting of community members review each child apprehension case. The following considerations are made in placing children who are permanent wards of the court, otherwise known as being “in the care of the minister”: the feasibility of placing the child with a member of the child’s extended family; and, where practicable attempts should be made to keep the child in an environment that is consistent with the child’s cultural background. Therefore, treaty status children living on reserves usually remain in their home communities, often in long-term foster care or custom adoption. Of The Adoption Act, Saskatchewan, (1989-90) Douglas states that:

There appears to be no preference within the statute or applicable regulations as to applicant status to foster parents or the suitability of adoption of Indian or Native children by non-Indian or Native applicants. (1995: 61)

However, the parents in my study said Native children are no longer adopted by non-Native parents. As (Triseliotis, Shireman and Hundleby, 1997) explain, transracial adoption is no longer “politically expedient.” The relative merits of foster care and other arrangements for Native children, versus trans-racial adoptions will be discussed in Chapter Seven. A framework for understanding attitudes toward and practices regarding transracial adoptions is presented in Appendix I.

Here, one more trend in adoptions must be addressed, for it explains, in part, why the parents in this study came to adopt Native children. Since the early 1970s the number of “healthy Caucasian infants” available for adoption has declined dramatically, primarily as the result of single mothers opting to keep their children, “Because of the decreasing number of infants available for adoption, an applicant waiting list was set up in 1974. This list facilitates the completion of a homestudy close to the time of expected placement” (*Social Services Annual Reports, 1977: 16*). As the number of available infants decreased, the number of couples wishing to adopt was increasing. This situation led to further restrictions being placed on couples who wanted to adopt an infant. An Advisory committee was established to tackle this problem, and they issued the following recommendations which came into effect August 1, 1976. First, a couple who wishes to adopt cannot already have more than one child. Second, the couple cannot have a combined age of less than 48 years, or more than 70 years (*Social Services Annual Reports, 1977*). The situation, however, continued to escalate so that by 1981 the average wait for an adoption was three years (*Social Services Annual Reports, 1981: 7*) and by 1982 this had increased to five years (*Social Services Annual Reports, 1982: 7*).

Given this lengthy waiting period, many prospective parents turned to the option of adopting a special needs child. In 1984 there were 190 families on a waiting list to adopt special needs children under the REACH program (*Social Services Annual Reports,*

1984). The “time barrier” led the parents in this study to adopt under REACH or, after 1987, “Special Adoptions” which they referred to as “accelerated programs.” An evaluation of the REACH program confirms this trend among adoptive parents:

While no firm judgments can be drawn from the data, the anticipated length of time a family is expected to wait when seeking the adoption of infants may have encouraged more families who would otherwise have adopted [infants] to consider the adoption of a REACH child. (Planning and Evaluation, 1980)

Two couples in the present study were excluded from adopting infants since they did not meet the Advisory Committee’s requirements. The other parents did not want to wait a few years since they felt they could not afford to waste any more time; they considered themselves “old.”

#### **4.2.2 The Adoption Process**

When the parents in this study decided to adopt a child they were all in their early thirties to early forties. They describe themselves as being “old” at that time.

Debbie:

[We were married a] long time before we even decided to have children, ten or twelve years, something like that. And when we found we couldn’t have birth children we went into the special needs adoption program because by that time we were getting long in the tooth. So we figured, whatever. That’s how we came to be a family.

Eva:

We were both older when we got married, I was [in my 30s] he was [in his early 40s]. It was the first marriage for both of us. We settled in [the city] because he had family there. I couldn’t have kids, and his sister got pregnant so we decided we wanted to have a family [too]. So we looked at a number of options including in vitro. My age was against me. So we looked at adoption and that’s how we got into adopting our two children.

The term “old” is, of course, relative. These couples were old in relation to the traditional age at which couples have their first children, following societal norms.

Since these couples were “long in the tooth” they chose to enter the accelerated adoption process which had the goal of placing “special needs” children. These “special

needs” children, also referred to as “hard to place” as defined above, are children who are not as attractive to young married couples as newborns. Apart from Eva’s son Cameron who had a cleft lip and palate, all the other children were deemed “hard to place” because they were Native, and in some cases older than two years. All the children were over a year old at the time of adoption. There was no indication that these children would later exhibit severe learning and behavioural difficulties.

The parents’ age, then, directly affected the type of child they were willing and able to adopt. With a small number of infants available for adoption each year, there was a long waiting list. Eva and Larry were too old according to the selection criteria to adopt an infant. Susan and Carl were also disqualified because they already had two children. The childless couples wanted to adopt as soon as possible, since they felt that time was running out. If they did not act quickly, they would miss the experience of being parents, they would never be “a real family.”

Feeling that time was against them, these parents decided to enter the accelerated programs designed to place special needs children described above. As Josie recalled, “I think if you wanted a white infant in our day it would have taken a long time as well. But not for the harder to place children. Mark was considered a hard to place child.” Debbie remembers that “it was about two years I think, because we went into the accelerated program because we agreed to take special needs children.”

The desire to have children to “complete” their families was common to all parents. Indeed, it is implied that a couple cannot be a family on their own, children are required to be a “real” family: “That’s how we came to be a family” (Debbie). Although Susan and her husband already had two teenage children at the time, they decided to adopt James since her children were eager to have a younger brother or sister.

#### **4.2.3 Native Adoptions**

As described earlier under “Adoption in Saskatchewan,” many children who come into care are of Native origin. While in the late 1970s through the late 1980s, when the children in this study were adopted, efforts were made to place Native children with Native adoptive families, this only occurred in a minority of cases due to a shortage of Native families wishing to adopt. As a result, many Native children continued to be adopted by non-Native couples. The shortage of Native adoptive families is the result of at least three factors: many families did not have the material means to adopt another child; communities were distrustful of social workers; and custom adoptions were favoured over formal adoptions (Daly and Sobol, 1993). Custom adoption is discussed further in Chapter Seven. It is defined as a traditional arrangement within a band, in which family members or others care for a child, so that the child can remain in the community and maintain contact with the birth parents:

The raising of children is seen as a communal responsibility with the immediate and extended family carrying the primary responsibility for a specific child. In addition to the input of grandparents, aunts, uncles, and older siblings, the parents, it is understood, may select a specific person to assume a special role in the child's development, teach necessary skills, and maintain a lifelong relationship with the child. Adoption in Native communities today does not only apply to children. A family may adopt a grandparent. A child may adopt an uncle or aunt. A man may adopt another as a brother and each will assume all the rights and responsibilities of a biological brother to each other's wife, children, and relatives. (Kimelman, 1985 from Daly and Sobol, 1993: 95)

As discussed earlier, funding is only available in the case of assisted adoptions, and only since 1987. Native people have reason to be wary of Social Services:

[Historically, c]hild welfare programs in Canada have not served Native families well, and have often undermined rather than supported these families. Children have been removed by child protection workers, often on trivial grounds, their extended families ignored as sources of care. Native children have been placed in various types of alternative care, ranging from boarding schools which were in themselves abusive, to foster homes, to white adoptive parents who have often been unable to meet the identity needs of Native children. (Bagley, Scully and Young 1993: 234)

Many of these children in care had been "apprehended" or taken away from their families because of neglectful or abusive situations. There is a definite dichotomy between the two classes of children available for adoption:

The number of children voluntarily admitted to care annually is affected primarily by the number of children born to single mothers and the prevailing attitudes towards illegitimacy. On the other hand, the number of children involuntarily brought into care is more indicative of the socio-economic status and ability of a certain segments of the population to provide the child with an acceptable standard of care. (Planning and Evaluation, 1980: 13, emphasis added)

Metis and Indian children accounted for over 50 % of all children taken into care by Social Services. Furthermore, they accounted for 58% of all children involuntarily brought into care (Ibid.). Why were such a high number of Metis and Native children in care? The policy of the time was to place these children with families who could provide them with "acceptable standards of care." While the definition of "acceptable" care differs with one's culture and class, in this case Social Services had the power to make this judgement.

Bagley, Young and Scully (1993) explain that social workers

[t]raditionally...have selected as potential adopters white, middle class couples of conventional behaviour and values and good material standards. Black and Native communities particularly have failed to meet such criteria. Adoption is indeed as Benet (1976) has argued, a political institution by means of which the poorer classes and immoral youth could be controlled by removal, with the additional benefit of meeting the needs of childless, middle-class couples. (p. 10)

Critics of the North American adoption system point out that factors such as poverty, unemployment, and poor health care lead to most cases of children leaving their family of origin and entering the foster care and adoption system (Ibid.) It is easier for Social Services to remove Native, Black and poor white children than to support families and communities to enable them to keep these children (Bagley, Young and Scully, 1993).

In Chapter Two, the poor social and economic conditions in many Native communities in this province were outlined. Such communities often lack the specialised health and educational services required by special needs children. While economic development and Native control over health care and education (which is occurring in many bands) are needed to remedy this situation, the immediate needs of children in care must be considered. Even Bagley and colleagues (1993), who are strongly opposed to adoption of Native children by white parents, concede that the best interests of the child can sometimes require out-of-community placement when a child has special needs.

Although the parents in this study were counselled about some issues they would have to deal with when adopting Native children, the full impact of their decision did not hit these families until their children became old enough to question their origins. The means by which parents help their children incorporate their Native background into their sense of identity will be covered in Chapter Seven. What some parents faced initially were some very negative comments regarding their decision to adopt a Native child.

Eva was dismayed by the reactions of some people when she told them of her impending adoption.

Eva:

When we knew we were getting Cameron and we were all excited and were telling people. The thing that really disappointed me was everyone had a horror story. Here I am I'm waiting for this placement and people say, 'I know somebody that adopted a Native child and when they turned thirteen or fourteen this happened.' There was only one person that I talked to that said, 'That's good' and didn't tell me a horror story.

When we first adopted the kids, actually I felt more

disapproval from the Native community than from the white community. I remember one woman came up, a Native woman at the farmers' market, and just stood there and stared. And you could just see the disapproval on her face...And looked at me and looked at Cameron, you know, and walked away. So I have felt some of that from the Native community more than the white community.

K: Has anyone said anything directly to you?

E: No, it's just a feeling that you get, and again not from the whole Native community. I mean there's some reason for that. There's a lot of history, there's a lot of hurt in this province. A lot of kids were taken away. But as [white] adoptive parents of Native children, whenever you see documentaries on T.V. we're always the bad guys somehow. At least that's the sense that I get. And I don't know whether that's changing.

Josie, who has worked closely with Aboriginal people described the following scenario.

Josie:

There is criticism and disapproval in general. No one has ever singled us out and criticised us. But I have been in situations [with Native people] where out-of-the-community adoption has been discussed and I have felt a degree of awkwardness and embarrassment about it. I talk very openly about it. I don't try and hide it in any way.

The marginalising effects of racism and the children's and parents' responses to it will be discussed in Chapter Seven.

#### **4.2.4 Parents' Opinions of Social Services**

It is only in retrospect that parents became aware of gaps in the assistance provided by Social Services during the adoption process. They could not have anticipated the problems which would occur, nor the way in which more complete background information about the children, and better follow-up care by social workers could have helped mitigate some of these problems.

At the time of adoption, parents were generally satisfied with the pre-adoption screening and preparation process, although Josie remembers being given only cursory information.

Josie:

We got him when he was three. And I do remember the male social worker giving us two articles on adopting an older child [but no other advice].

Eva and Larry were instructed to research cleft lip and palate in order to prepare themselves for the many surgeries their son Cameron would face, and the psychological implications of this condition. Their younger son Tim was language-delayed at the time of placement and his parents were required to take him for a speech and hearing assessment. As will be discussed later, this led to a timely diagnosis of FAE and early intervention services.

None of the parents felt that they had been misled in any way by Social Services regarding their children's condition. FAS/FAE was not well known in the late 1970s, and even a decade later when the youngest children were adopted, information was sparse. As Eva explains,

Eva:

[When we adopted Tim]we had some mention in the background that alcohol was involved but Fetal Alcohol Syndrome was not mentioned. And we were not really aware of it at that time. I'm not sure that social workers were.

When asked if social workers suggested that her son might have special needs Josie replied

Josie:

No, nothing. Remember, they hadn't identified FAE then, it was 1978. The social worker in (town) gave us some articles about adopting older children, that was it.

Debbie, however, did hint that social workers had been overly optimistic in their assessment of her daughters' health.

Debbie:

...[O]ur daughters were... special needs because they were First Nations not because they were identified as disabled. They had clean bills of health. So it's only subsequently that we learned of their disabilities. We didn't know that any of the [other] children [in the family] or the mother was affected at the time...of the adoption. I think everyone was hoping and praying that it wasn't the case. But, that was not to be.



The only surprising aspect of the adoption process which some of the parents reported was the short time between a suitable child becoming available and the arrival of the child in the home; and for others, the brief period from enrolment in the program to the placement of the child. Parents were not upset by these circumstances, merely startled, since the adoption workers had implied that they might have to wait a couple of years for a child.

Paula:

They had quite a long sort of screening process and everything. And then they said, 'Oh you can expect to wait two or three years, especially a single person. Because we do look at the child's best interest you know, try to find the best home.' And within three months I had a child, you know. And it was really exciting. Yeah, so there I was with this three-year-old kid just like that, you know. It was really good.

But it was a really quick placement. I just drove down with the social worker...And we stayed over two nights in a motel and Jason, he visited the first night, slept over the second night and then the worker drove us back to [the city] and put us on the bus ... She had another placement to do. So ... it was a real kidnapping I'm sure as far as Jason was concerned. He was fairly agreeable and he was really verbal, really social, quite capable and kind of independent. And it wasn't until we got on that bus that he was beginning to wonder if this was such a good thing. And meanwhile the worker had taken his tricycle and his box of toys. We just had his suitcase. And that was worrying him a lot, that [she] would remember to bring his bicycle.

Eva:

And basically after the first meeting you make a decision about whether you want to go further. We said we did, and they said, 'How soon would you like him?' He arrived here at 13 months, two weeks after we accepted him. We could have actually had him sooner I think. I needed to give notice at work, and it was sudden. Yeah, so we needed those two weeks to prepare ourselves as well.

There was a waiting list even to adopt special needs children, but social workers may have been overly cautious in suggesting the long waiting period, not wanting to give prospective parents false hopes of a quick placement.

#### 4.2.5 Single Parent Adoption

I will discuss Paula's experiences with fostering and adopting children in detail since she is unique in this study as a single parent. The changing attitudes of Social Services towards single people adopting, and corresponding changes in policy, mirror societal changes which took place between the late 1960s and early 1980s. Her story also illustrates how the comments and suggestions of social workers reflected the image of the "ideal" family endorsed by Social Services.

Paula:

The program that was operating when I adopted Jason was called REACH. It was Resources for the Adoption of Children. ... both my boys actually had ads in the paper. You know, they'd have this 'Today's Child' ...in the [newspaper]. And they gave him a sort of pseudonym. But they each had nice sets of pictures that had been taken of them for their newspaper. ... I think they were all older children mostly or sometimes family groups as well. You know many of them were Native kids or kids who for some reason were more difficult to adopt...Some of them had handicaps...And they'd give you their story you know, always really positive. ... I had applied for adoption five years before that and they had a program called AIM which is Adopt Indian and Metis and I think it was similar. It was sort of a proactive thing to adopt these kids.

Two years later Paula decided to adopt another child, a little brother for Jason. This adoption was fraught with tension and went anything but smoothly.

Paula:

Brad had been placed, and was actually with us for adoption, and his natural mum applied for custody again. So they ... closed the adoption, and were going to move him. And he couldn't go back to his old foster home because his foster grandma had left town and it wasn't going to work out for her. And so I said, 'Well, I would like you to place him with me, to keep him here. I'll take him as a foster child until this is all straightened out.'

So, right after that we were involved in visits...and we came and went quite a bit. And finally we did...an adoption with access. Her lawyer and my lawyer drew up the papers and we confronted Social Services with it, and they actually didn't want it. And we went in front of the judge and they did the adoption first, and then the access. And so we've had a fairly good relationship through that point ... and then quite a period

of time where there was very little contact. And then about the time when he was around eight or ten we started visits again.

Yeah it was just getting to be a very positive thing for single people to adopt. The first time when I went to the AIM program ... they flatly refused. But the irony of it is that they persuaded me to foster. So I fostered a kid in between. And then the worker that I had for this foster child [said that] it looked like he may be adoptable. But he wasn't. He went back to his mum. But the worker that I had said, 'You know, you don't really want to foster. What you really want is adoption, and our policy has changed. You really should apply.' So I applied again and it took quite a while. I think they were more rigorous with a single person. The worker I had was really good at counselling and making sure that I knew what I was doing. There was clearly a change in policy from three or four years before. And of course I was older and I had a job. You know, my circumstances were different and maybe that was part of it.

And ...by this time they had this REACH program that was a little different too... Actually one of the things that sort of swayed it was the foster family had a child placed with a single person before, and was able to keep up a nice relationship with the child because it was easier than with a whole family. And so they were kind of pushing for it too. By this time they were allowing foster families to go to adoptive homes, and they did an open sort of placement. .. I went down and stayed a couple of days there and that kind of thing. So they knew who I was. I think everything changed quite a bit in a few years with adoptions.... And the foster child I had [earlier] was a little boy so I had lots of boys' things so it worked really well for me to have a little boy. I said I'd have either...I think one of the workers would have been more happy if I'd adopted a girl, that a single mother should adopt a girl. But I was pretty easy. I was even thinking, 'well I only have brothers, and my brothers have boys, when it comes to my whole family a boy would be a really good fit.' Then [when I wanted to adopt my second child] it was really funny, the stereotype, because the worker that we had really wanted me to adopt a girl since I already had a little boy, for the set. But Jason and I had already talked that over and Jason didn't want a girl. But you know, it was sort of light hearted but there was this, 'Are you sure? I'd just assumed it would be a girl.' And Brad was even younger [than Jason]. And I'd decided that I couldn't manage a child that couldn't fit into a daycare centre, so [he should have been ] toilet trained and pretty independent. And then here was this, Brad at two wasn't independent at all, he was still very much a baby. But it worked out very well.

Paula adopted her first son in the early 1980s. Just a year earlier, Social Services

expressed the need for policy changes regarding single parent adoptions:

Current practices do not encourage [but do not prohibit] the adoption of children by single parents. However, this issue is likely to emerge in the future as a policy question for both CAR [Central Adoption Registry] and REACH. It becomes a particularly sensitive area for the REACH program where there are generally more children seeking adoption than suitable homes available. (Planning and Evaluation, 1980: 5-6)

And,

Social attitudes towards single parenting are beginning to change. In the past, single parent families were considered to be a poor environment for child rearing and breeding grounds for juvenile delinquency. [However],...the social problems related to single parent families are more a function of income rather than marital status. (Ibid.: 6)

While the phrase “breeding ground for juvenile delinquency” may strike us as outdated, the notion that “inadequate” parenting leads to a proliferation of young offenders on our streets is alive and well. The parents in this study [both single and married] were often blamed for their children’s behaviour. The frequent brushes with the justice system which many parents of adolescent children with FAE face will be discussed later in the Chapter Seven.

### **4.3 Adjusting**

*Adjusting* delineates the process by which parents and children develop a relationship, and come to feel that they are members of a family. Parents were prepared to deal with the effects of their children’s difficult beginning. All of the adoptive parents had been informed by social workers’ case notes or members of the biological families that their children came from impoverished and sometimes abusive homes and some knew that alcohol was part of the picture.

Paula:

And what I was told was that he had been placed in care because the aunt, who was looking after him, couldn’t manage him and her own children, so they were all placed in care. ...the mum by this time was in a coma and in a nursing home because of a drug overdose or misuse. And she was certainly an alcoholic and on drugs and they were out of control.

They ascribed their children’s behavioural differences, however, to neglect and general deprivation of their environment, rather than to the adverse affects of alcohol in utero. Parents believed that with love and parental guidance, good nutrition and medical care,

and a little extra help their children would soon catch up with their peers. This perhaps overly optimistic belief was a position commonly promoted by adoption workers, based on research on adoption outcomes which fuelled the permanency movement mentioned earlier. Although these children were placed in very enriched environments, they displayed behavioural and emotional problems which led their parents to seek professional help. In some cases, parents did not notice any problematic behaviours in their children until they reached school age.

We have established that from the parents' perspective they had been given incomplete information about their children's backgrounds and potential health problems. Although they had a general idea about the type of families from which these children came, their biological heritage and early experiences were shrouded in mystery. Parents strived to gain control over this incomplete history by claiming the children as their own, by pushing thoughts and images of the biological family into the background while they concentrated on achieving the the goals of adjusting and *living as a family*.

The process of adjusting is a time when adoptive parents and their new children get to know each other, gain familiarity and comfort in their new roles, and finally, form bonds of affection and belonging. Indeed, according to the emerging field of "the psychology of adoption," an important psychological milestone for adopted children is to form emotional attachments to their adoptive parents. Likewise, parents must form bonds of affection with their children (Triseliotis, Shireman and Hundleby, 1997: 35). Researchers have documented a correlation between the age of the child at adoption and the ease of the adjustment process: the younger the child at adoption the easier it is for children to form bonds with their parents (Boyne et al., 1984 and Planning and Evaluation, 1980).

In Western societies childrearing takes place in the context of nuclear families, with the mother taking the primary role. Consequently, research has focused on the relationship between mothers and their children, or the "mother-infant bond." Bowlby's (1951) pioneering study on maternal deprivation and mental health provided a foundation for understanding the impact on children of separation and loss from people to which they are attached (Triseliotis, Shireman and Hundleby, 1997: 27). His contention, however, that children over two years of age were unable to form new attachments has been unsupported by many studies on adoption outcomes. Indeed, although separations and deprivations are harmful to children, they are resilient and "[given] an accepting and loving home, many [children] have the capacity for recovery from adversities, unless these were too severe and prolonged" (ibid.). In the present study, the children who were most neglected and abused in either their biological or foster homes had the most difficulty bonding with their adoptive mothers. Only time will tell if their early abuse was "too severe." The following stories paint a vivid picture of the tumultuous early life of three adoptive families. From the day they entered their new families, Mark, James and Tim

acted in ways which were either extremely disruptive to the whole family or frustrating and upsetting to their mothers.

#### **4.3.1 Josie: Lots of Layers of Things**

Josie:

Well, when he came to us it was quite a change for him, quite stressful. He'd been in his foster home for 18 months. When we got him he was three and he was toilet trained, but within two weeks he regressed in his toileting. We had him in diapers for two whole years after this until he was five.

K: Was there anyone you could talk to about this, anyone you could turn to for advice?

J: We were living in a remote village in Peru at the time, so in a word, no.

K: That's not a typical situation. Please tell me more about it.

J: We were working at a hospital in a small village in Peru. It was very remote. There were two very good doctors there, but we didn't feel it was their place to deal with this. I'm not saying they weren't knowledgeable, but they had enough on their hands. So we just dealt with it.

It seemed initially just like having a little visitor in the house. A playmate for Ian. To have these toilet habits regress I found annoying and frustrating. And I didn't find him overall to be a terribly endearing child. He wasn't very physically attractive. He started out as the typical pot-bellied uncoordinated spindly legged little kid, with flat feet and huge knobby knees. We took him hiking though, and he gradually developed and got more strength.

I certainly wasn't good with him in the beginning, because I had this enormous love for Ian, and just flat for Mark. So then I started to feel guilty about that which compounded the strain.

We only had him for two and a half months before we left for Peru. Then we were on the road: down to Ottawa for orientation ...and more orientation when we got to the capital of Peru. And then the move up to the village to where we would live. So there was a period of at least two months of great transition, and that was okay because we were all busy and focused on these things. And then we started to settle into our life there. And Ian and Mark got along very well so that was a good match. But again I found him not a child I readily

loved or took to. So that continued to be difficult.

K: So it took quite a while then.

J: Oh another two years it took. Hard work...he was different. He was actually quite cheery most of the time. He'd wake up at night (I think I mentioned this) and have these horrible nightmares, and be inconsolable. He'd scream for half an hour. He'd just sit up in bed and scream and scream. He wasn't asleep and he didn't seem to be awake.

K: But Mark wasn't very disruptive in the beginning, other than...

J: No, he wasn't disruptive he was [long pause] he was indiscriminately charming. Other people thought he was cute. But he wasn't at all discerning. He didn't differentiate us from anybody else. He could climb onto our lap or he could climb onto any other adult's lap. So he just seemed to be [pause]. It never seemed like he recognised us as a family, and maybe he didn't.

J: I don't know what a three-year-old thinks and he'd been through a lot of change. And maybe he didn't know who we were, whether we were to be any different from any of the other houses that he passed through. But that was difficult for me.

K: I think that's quite common, that kids with FAS/FAE are very friendly to people, but you wouldn't have known that then anyway.

J: Oh no, no. I thought there was something wrong with us, that he didn't bond with us and then that made it more strained for me to bond with him. And the more strained it was for me, the more guilt I felt. And then the more strain that would put on the relationship. Lots of layers of things (Josie).

She remembers some of Mark's positive qualities in those early months.

Josie:

He was very sociable, indiscriminately sociable. He ate well, slept well. He related well to both adults and other children. He was a good brother to his brother who's a year older. He's very adaptable. He came from his foster home to northern Saskatchewan, trailer living, to Peru in 6 months. Besides the regression in toileting I think he came through it remarkably well.

#### 4.3.2 Susan: It was Really Intense

K: Could you tell me what it was like for your family when James first moved onto your home; when you first adopted him?

S: Oh, do you really want to know that!?

K: Well, you can tell me a little about it.

S: Okay, a little. ...James did not have language when he joined our family. His method of communication was screaming in high tones, low tones, medium sized tones, loud and soft, mostly loud. He took what he wanted, he grabbed things. He did not know how to use a fork and a spoon, ate with his hands. It was actually a real culture shock...

I think I had more of an idea of what it was going to be like than anybody. Scott was really enamoured with the idea of a playmate, a little brother, the little brother he never had. That was shattered time and time again. James destroyed his things. We had to start boxing things, putting things away. And James was not allowed in Scott's room. That meant nothing to him. We had various methods of locking the door. I remember Scott crying a lot. He grew up a great deal, it was good for him in many ways. He'd been sort of a mama's boy up 'till then. He still is in a way, but in a nice way. He and I have a very close relationship.

For Kelly, Kelly spent far more time reading a book, and my husband spent more time away. And that's how they coped. So the majority of working with James was left up to me. In hindsight, I think I should have made them help, but maybe they couldn't at the time.

My husband certainly was not prepared for the intensity. I think he was prepared for [the fact] that this was not going to be easy, but most certainly not the intensity of it. I don't think he even imagined, even though I kept telling him [before the adoption], 'You do understand sweetheart, that life as we know it is going to have to change here with this particular child, because it's going to be a real hard struggle.' And I don't think he realised how intense. And that's the word he always used, 'This is intense.' And it was.

We needed patience, perseverance more than patience. Kelly decided that she was going to teach him how to talk. I had taken the Hannon speech and language course a second time. I'd taken it once as an educator, now I was taking it as a parent. That was really good. The lady that was leading that from the university, oh she was excellent. Kelly would just repeat the same word [for him]. I remember one morning, James would say 'watsada watsada' and that would mean



'what is that?' We finally did ascertain that one day. And she said 'tractor,' because he was pointing at the tractor in the yard. I think between the two of us we must have said the word[tractor] sixty times. Not that James would say it. He would just continue to say 'watsada' and he would throw things.

I'd be willing to do it again. I don't want to make it sound like it was really negative. He was a cuddly little boy; he loved to snuggle. It was really sweet to do that with him. He had a thing for hats. Anybody that came [to our house] who had a hat, he would take it and put it on and dance in the kitchen, and he would look really cute. He was two and a half years old and he was a little porker and he was a real charmer. He had such a gorgeous smile, which you don't see very often these days. And twinkling little brown eyes. And he loved to cuddle and I know he needed a lot of that. I think that's where Scott had to grow up because Scott, even though he was older, often would sit beside me and hold my hand. Even in the city sometimes, even though he was really too old to be doing that. And yet I'm not too sure what's too old. James is nine now and there are times when we're in the city he feels threatened and he needs to hold my hand.

Nights were really tough. He did not sleep for long periods of time. I think we were all really tired. But I never lost the thought that God meant this child--not that God planned his mother to drink or anything like that, she chose that herself--but I think that God chose for that child to be in our family. And that sustained me over and over and over again.

Also at that time I was very heavily involved in a Bible study. ...There were two other families who were living close to us at that time who had adopted children and had gone through, not quite as intense as this, but had gone through frustrations. It was good to pray together and be together. They were very supportive .

And another couple who since have split up unfortunately. This gal was really really supportive, would bring her children over to play with James, knowing how difficult it was for me to take him out. He hated being in a vehicle. Screamed and screamed and screamed [when he was] in a vehicle all the time.

So you change your life. If the child would have been born to us this way, or would have been born with any physical deformity, you would learn to adapt to it. That's what you do I guess.

We didn't [pause] yeah, looking back on it now I think 'How did we survive that?' But we did. And actually if you looked at the little boy that came to our house and looked at him now,

he has made such great strides. He has done very well.

#### **4.3.3 Eva: It was a Difficult Placement**

Eva begins by explaining that they adopted Tim at the age of two. Before the adoption, he had a very rocky couple of years.

He had been apprehended at three months, quite by accident. His mother had left him with family and failed to return so they called Social Services. At that point he was put in a foster home. The doctor said in another 24 hours he would have died from severe malnourishment.

...He stayed in the foster home except for a short period when the foster father was ill...My assessment of the foster home, they were an older couple... I think [at the foster home] he got lots of hugs and loving that way but he spent a lot of time in his crib. So when we got him at two years he couldn't feed himself. I shouldn't say couldn't, he had never been allowed to because it makes a mess. I don't think he'd ever really been allowed to run. So when we got him he was pretty busy, a very busy child. He also came--although the forms didn't say that and the foster parents didn't say-- we believe, with zero language. He didn't even respond to his own name. He's a master at reading body language and tone of voice. And he fooled us for a while too. ...we think the only word he recognised was 'no' at two years. So that was very difficult because we had a child that was physically two years old but mentally and emotionally basically at newborn level almost. So we couldn't say, 'Tim don't touch the stove, you'll burn yourself' because he didn't understand any of that. So it was a very very hard placement.

...[He]e saw a physiotherapist for a while because he walked on his tiptoes all the time. And she checked him out. It wasn't a physical thing. The only thing she could figure out was he stayed in his crib a lot [in his foster home] and so he stood on his tiptoes to look over the bars. So what happens--it's like a woman wearing high heels--the tendon tends to shorten. ...like some kids with certain disabilities are born with short tendons but his wasn't like that. So, actually she was going to put him in braces. And we tried a pair of really thick soled shoes where he couldn't get up on his toes, and that was the last thing we were going to try before the braces. And that seemed to rectify it.

He also didn't bond. He liked us well enough, but then he liked everybody. I'd say it was six months. And I really had a hard time with the bonding with Tim. It wasn't a positive placement for me. Because he was so busy, and I was so tired, and he was so difficult. And it was so different from Cameron who bonded instantly. Because you're doing all of

this and yet the child doesn't prefer you over anyone else... you're not getting any of the rewards. But we have a strong adoptive parents group. We didn't have any help from Social Services. With Tim we went through four different workers. We'd see one worker one time and by the next time [it would be another]. And for a period of time we didn't have any worker. And that was problems...they had internally, it didn't have anything to do with us particularly, but nonetheless there was no support. If we didn't have a strong adoptive parents group I could have been in, you know, very serious trouble. Because it was a very hard placement. Since then he's become an integral part of the family. He's bonded and he's done remarkably well. He's just a really pleasant child to be around.

Eva contrasts her experience with Tim with her first time as an adoptive mother with Cameron, in which the bonding process went very smoothly.

Eva:

He was given up at birth by his mother and went from one hospital to a foster home, very good foster home, and then he came here. So he's always had that consistent bonding, and bonded very easily when he came here, because he had the love before and was able to transfer that.

#### **4.3.4 The Importance of Bonding**

According to Triseliotis et al. (1997) adopted children, unlike those who grow up with birth families, must accomplish a number of specific psychological tasks:

1. Reattachment to new parent(s);
2. The awareness of being adopted, which in turn involves:
  - (a) the knowledge of being adopted and the gradual understanding of its meaning and implications;
  - (b) access to genealogical and other related information;
  - (c) the notion of two sets of parents and the acknowledgement of the differences involved; [and]
  - (d) dealing with the sense of loss of the original parents and the element of rejection that it conveys.
3. The formation of an identity that includes the above attributes. (Triseliotis et al., 1997: 35)

A close examination of adoption policy and procedures will shed light on the concern over successful bonding shown by the mothers.

When a child is placed with his or her new parents, there is a trial period before the adoption can be legally finalised. This is called the "probationary period." Parents are on probation and their success is measured thus: "The worker looks for signs of

emotional bonding between the parents and child, the child's adjustment in the community and the general adjustment and well being of the family" (Planning and Evaluation, 1980: 24). If the mother is feeling tense and inadequate, this can hardly ease the adjustment of the family. Further: "The family applies to finalise the adoption legally when they, as well as the social worker, feel the adjustment is normal" (Planning and Evaluation, 1980: 25).

A tremendous amount of pressure is placed on the adoptive mother to bond successfully with the child. The measurement of this success is carried out by an individual social worker, through the filter of his or her own biases. Who decides what is normal? Mothers in my study who had no biological children, reflecting on these early years, said things like "maybe there were things that I was missing, that were different about him because I couldn't compare...I didn't have any regular children" (Eva). At that time they had enough confidence in Social Services to defer to the social worker's judgment.

From the descriptions of the children, we learn that Mark seemed happy from the beginning. Similarly, James, while his behaviour was more disruptive, was also very cheerful most of the time. Their mothers, on the other hand, recalled feeling frustrated, tired and inadequate during this time. From the children's point of view, their needs at this stage of their lives were being met. The slowness of the children to form bonds of affection with them, however, was extremely distressing to their mothers.

The issue was not that the children did not respond emotionally to their mothers, but that they did not respond positively to them exclusively. They did not make them feel special, different, mother-like. Furthermore, there is evidence that these children's emotional responses were atypical: Mark and James were perpetually cheerful and, as Susan explains, James had to be taught what "feelings" meant.

Susan:

He's not good at recognising his own feelings; we never saw him cry. Screaming and crying are two different things, right? And I'm sure he was, ... five before we actually ever saw him cry with real tears. And yet he would always say 'I'm so sad, I'm so sad.' But he would have this happy little smile on his face. [So I would say] 'Usually when people are sad, sweetheart, they have tears in their eyes.'  
And he would try. I remember him licking his fingers and putting them on his eyes [and saying], 'They're here mum.'  
But he just wasn't aware, and still isn't in many ways.

This lack of emotional depth was compounded in the case of Tim and James, by their underdeveloped verbal skills.

When the children did not "bond" soon after coming into their adoptive families, Eva and Josie felt that they were not doing a good job as mothers. This lack of

confidence in their mothering skills caused them to become anxious and frustrated, and may have adversely affected the way they interacted with their children. Josie presents this picture most clearly, and her lack of support from other adoptive mothers may account for the prolonged period, about two years, that it took for her to feel strong emotional bonds with Mark. While Eva also struggled, she was able to overcome this problem within six months. It is interesting to note, that while Susan recalled being exhausted and stretched to her limits during the early months as an adoptive mother, she did not even mention the terms “bonding” or “attachment.” She phrased the problem at hand as getting over “culture shock.”

Susan describes how she had to learn her son’s form of communication (ie. that his screams were not random but indicated needs) and gradually taught him how to communicate in English. This little stranger who screamed and ate with his hands was quite a mystery to the whole family. From James’ perspective, this new home was likely just as confusing. Next, as communication improved and these two individuals got to know each other, trust was established and James began to learn in strides. Both James and his mother had overcome their initial sense of strangeness and had become familiar to each other. In other words, they had bonded.

In this study Josie was both geographically and emotionally the most isolated. Both Josie and Eva, however, who had more emotional and practical support from other adoptive parents, describe going through many of the same experiences and feelings. Indeed, Josie and her husband managed to weather this difficult time by supporting each other. Through the children’s early years they took turns being the primary caregiver. They have always shared tasks, and communicate effectively and often to each other. Eva, on the other hand, relied heavily on the adoptive parents association. Her comment, “... I could have been in very serious trouble,” shows that she often felt near the breaking point. As Susan’s story reveals, while her family provided little support in the beginning, she took comfort in her faith, and received needed help from friends and neighbours.

By the period of *adjusting*, when difficulties with bonding were experienced, Social Services was unhelpful or completely absent. In analysing their practices with these families it would be fair to say that their mandate was to place children. After that, it was up to the adoptive parents to make the placement successful. This assertion is strengthened by the following policy statement: “Once an adoption is legally finalised, the contact between the agency and the adoptive parents ends, although counselling and referral services are available upon request” (Planning and Evaluation, 1980, 27). In reality, as we shall discover in the following chapters, these services were often inadequate, nonexistent, or had long waiting lists.

As early as 1971, Saskatchewan Social Services was aware that parents adopting under the AIM program were requesting both more background information about their children and their birth families, and more support following the adoption (Planning and

Evaluation, 1980). From their perspective, they had addressed these problems in the REACH program (Ibid). When Social Services cannot meet the needs of adoptive parents and their children, the adoptive parents association, other parenting groups, friends and family must fill in the gaps.

From the parents' point of view, Social Services should provide ongoing support; adoption does not end with the placement of the child, but is a process of forming a family. Social services believe they have accommodated the needs of parents by encouraging the formation of adoptive parents' associations, which have the role of providing advice and support:

The long range intent of this involvement by the department should not be to become the "provider" of the service but rather to stimulate the development of resources in the community for adoptive parents. The intent should be to foster the development of adoptive parents' associations and resources. (Planning and Evaluation, 1980: 82)

A major flaw in this plan was the lack of recognition that these parents are often in crisis themselves, and cannot always be supportive. These are unpaid services, which individuals are expected to perform as an act of altruism, and as a condition of their status as adoptive parents. Their feelings of abandonment by Social Services will be a recurring theme in the coming chapters.

#### **4.4 Living as a Family**

The adoptive families in this study began as three childless married couples who wished to adopt a child, a biological family with two young teenagers who wanted to adopt a younger child, and a single woman who was previously a foster mother, who wished to adopt one of these children. The previous parts of this chapter discussed the adoption process and the period of adjustment which is experienced by all adoptive families. The present section will explore the process of *living as a family*.

*Living as a family* entails consciously acting like a family. Parents and children partake in activities together, as a family. As well as enjoying themselves and strengthening family ties, they are advertising their status as a "real" family, with the same rights as biological families.

As discussed in the previous section, adoptive parents learn about parenthood and what a family should be like from social workers, other adoptive parents, and their friends and family.<sup>2</sup> Paula was the only person in this study who had fostered children for several years before she adopted her sons. This allowed her to experience parenting first hand. Susan and Carl had already raised both a son and a daughter and were experienced

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<sup>2</sup> Images of the family in the media undoubtedly have an effect on adoptive parents, but this was not mentioned explicitly by the participants in this study.

parents. As Susan described in adjusting, however, this did not prepare them for raising James. As she put it, their family had to change their lives to adapt after his arrival. *Living as a family* is a stage through which adoptive families pass, which enables them to become a cohesive family unit. The stage of *adjusting* must be completed more or less successfully before *living as a family* can proceed. Three important elements of *living as a family* are *being a family*, *being together*, and *living the dream*.

#### **4.4.1 Being a Family**

Traditionally, adoptive families have been advised to model themselves after “natural” or biological families. Their particular needs, stemming from their status as an artificially created family, a social unit based in law, were ignored (Kirk, 1985). Kirk explains that this “rejection of difference” is displayed by the family acting “as if” they were a natural family. To maintain this fiction, any thoughts of the child’s biological parents are repressed, and the child is told about his or her adoptive status only when they are “old enough to understand” or perhaps not at all. Keeping up this charade often caused tension within the family, and resentment in the children when they learned that they were adopted. While adoption agencies advised parents to tell their children about the adoption “when the time was right,” they did not tell them how to approach this delicate subject (Ibid.).

In contrast to this traditional approach to adoption the families in this study practice what Kirk (1985) calls “acknowledgement of difference” which means recognising the special nature of adoptive families. This special status allows adoptive parents the freedom to seek help with their parenting, and usually entails keeping some kind of connection with their children’s biological families even when it is not a formally “open” arrangement. This contact ranges from visits with natural parents or siblings to simply teaching the child about his or her cultural background.<sup>3</sup>

#### **4.4.2 Being Together**

By doing things together as a family adoptive parents and their children get to know each other, learn their respective roles, and gradually think of themselves as part of a family unit. Rather than everyday routines like eating meals together, when parents spoke of “family things” they mention playing games, riding bikes and other forms of recreation, and taking vacations together. Most of these activities were carried out in public places where other families were present.

Susan’s definition of “family things” are activities which take place at home on the family farm. This different approach is influenced by two factors: their relative isolation in a rural area; and the fact that her family was already established. Rather than showing that they are a “real” family, their object was (and is) to make it known that James is as

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<sup>3</sup> These cultural activities are discussed in Chapter Seven.

much their child as are their biological children.

Susan and Carl already had a family, and while they had to adjust to James's behaviour, he was expected to conform to many of their routines such as going to church, and helping with chores around the farm and house. They placed a high value on family activities. When James was adopted he was incorporated into this lifestyle.

Susan:

We try to do a lot of family things. We like to play a lot of board games, I guess like to watch TV together. Well, not really TV but videos...we like to rent a family video. In the wintertime we have this big slough close to our house and we clean off a big section for skating and everybody skates. [Also] in the winter we do a fair bit of tobogganing. The same big slough is used in the summertime for kite flying. My oldest son is very good at making kites.

A vital part of this family's life is their Christian faith.

Susan:

We are a Christian family and our faith is very important to all of us ... we have devotions as a family together and we also pray together. Individually the kids will do that with [James] also. An ordinary reaction to a crisis for both my older two kids is to say to James, 'Let's stop for a minute and think about this, and why don't we pray.' It actually is a bigger calmer for James than to say, 'Excuse me, could we have a time out here.' He will actually respond to that much much better.

Parents introduce their children to some activities which they enjoyed before the adoption. Hence they are socialising their children to have the same values and enjoy the same pastimes as themselves. Some sports or hobbies may be strategically chosen to enhance the child's strength or coordination, others to help them learn to relate to other children. Most important, the parents in this study stress the value of a cohesive group of people who like to do things together. Because their children have poor social skills, parents must make an extra effort in their own interactions, by communicating and cooperating and sharing the burden, to make things run smoothly at home.

#### **4.4.3 Living the Dream**

This stage of life was remembered fondly by Josie, Paula and Debbie, who reminisced about a happier, less complicated time. While Josie's children are now young adults and in relatively stable circumstances, their teen years were a horrendous time for the family. Debbie's family has been living in a state of crisis for two years and she is



very apprehensive about the future. Paula's older son will soon be released from jail, and she is fearful that he will discover her location. Given the the intensely negative experiences which these women lived or are living through, it is not surprising that they remembered the past as a sort of golden age, or ideal way of life. Any problems which may have existed at the time were either not identified as problems, or have paled in comparison to later and current troubles. This time was only described as a "dream" in retrospect.

It is interesting to note that all the families in this study enjoyed camping when their children were young.

Josie and Bob involved their children in many activities which were part of their lives. They both work in the health care system, and have been involved in advocacy and development work overseas.

Josie:

When the boys were younger we took holidays, [to a resort] or skiing. We would go to the boys' sporting events, mostly soccer. We took the boys to social functions, either at home--we had large functions here, quite a crowd related to solidarity work--or we'd take them to parties or benefits.

Debbie and John have always taken canoeing and camping vacations, and when the girls came along they introduced them to these forms of recreation.

Debbie:

John and I have always done that. These are from when they were little [brings out a framed collection of photographs]. I always pull that one out because that's our dream picture.

K: Which one, the canoeing?

D: Yeah, doing things like that, together like that. And we could still all fit in a canoe at that point. And it's not a very difficult trip to do with children.

Debbie is emphatic about contrasting this "dream" with the current reality of her family's life which at times can be nightmarish.

Debbie:

This is a while ago, about three years ago I think, in happier times. They were actually still able to sit next to each other. The pictures I showed you are...the kinds of things we used to do a lot. Unfortunately, because my older daughter's

behavioural difficulties<sup>4</sup> are such now that it's extremely difficult to do things as a family unit. So the kinds of things we do by choice now are...we have to split our daughters up quite a bit .

Their present situation will be examined in Chapter Five.

#### 4.5 Summary

Debbie captured the essence of *living as a family* most effectively.

Debbie:

We, I think, did a lot of things as a family unit. We tried to anyway, and we really enjoyed that. We did lots of camping, travelling, visiting. Lots of things like bike riding. All those kinds of things. ... I'm not sure that's the way we were meant to be anyway, but because we had to make this obvious choice to bring children into the family we really went at it like that's what we wanted to do.

Apart from allowing the burden of raising the children to be shared by both parents and older siblings for a short time, these activities are described as being enjoyable in themselves for the whole family. For the children, these times provide opportunities to strengthen emotional bonds with their parents and siblings, and grow physically and socially by enhancing their physical strength, coordination, and social skills in the safe environment of the immediate family.

It is important to point out that *living as a family*, while presented here as a separate entity for analytical purposes, flows from activities enjoyed before the adoption and blends into the stage of *living day-to-day* which follows. The skills discussed above which are developed when the children are very young, serve as a foundation to be built upon as children make the transition to peer activities in mid to late childhood. Furthermore doing "family things" remains a part of the children's lives during *living day-to-day* --and even sporadically in *falling apart*--but these pursuits are less frequent, not as intense, and less self-conscious. Finally, the family provides a foundation on which to build the local community which will be discussed in the next chapter.

Josie provides an excellent example of this principle by describing how physical activity first carried out as a family when Mark was small, followed by team sports when he was older, was of benefit to her son.

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<sup>4</sup> Kate, their older daughter, has been both verbally and physically abusive towards her younger sister for the past two years. She is much larger than Becky and, in her mother's words, "capable of causing her serious bodily harm."

Josie:

He started out as the typical pot-bellied uncoordinated spindly legged little kid, with flat feet and huge knobby knees. We took him hiking though, and he gradually developed and got more strength. Swimming was really good for his coordination, and it trained him for other sports. We got him into soccer. Now, he certainly didn't have any kind of natural aptitude for this. It would take him two or three times as long to catch on... There was definitely a lot of coaxing involved. But, as I said, I think he really appreciated this when he got older. And I think it made a big difference in his physical development.

Mark has carried these interests into adulthood. He likes to shoot baskets and play soccer for pleasure.

In the next stage, *living day-to-day*, further examples of ways in which the children are encouraged to take part in activities such as these in order for them to both remedy some delays and capitalise on their strengths will be presented.

This chapter has discussed the early years of the adoptive families. The major issues presented were the adoption process itself, and the period after adoption when parents and children must "bond" or form feelings of affection and attachment. The difficulties in bonding experienced by some of the mothers and children were portrayed, as well as the impact of the adopted child on the whole family. Also, parents' perceptions that Social Services did not meet its responsibilities in helping them after the adoption was finalised was explored, and it was discovered that this belief stemmed from conflicting definitions of adoption.

Social services sees adoption as the matching of children with suitable parents, and allows for a brief period of adjustment before the adoption is legally finalised. Parents, on the other hand, view adoption as a long-term commitment to raise a child to independence, which they should not be expected to carry out alone. These issues will resurface in the chapters which follow. Finally, parents consolidate their status as and comfort with being a family, by participating in activities which they all enjoy together. *Living as a family* does not mean imitating natural families in every way. Rather, it is a means for adoptive families to validate their status as a family with all the rights enjoyed by biological families in our society. This time of life, fraught with difficulties as it was, is remembered fondly by mothers, since even more trying circumstances were to follow.

When *living as a family* has become routine, usually after the first two or three years, parents become aware of the extent of their children's special needs, and begin to focus their attention and energy on meeting these needs. I have called this stage *living day-to-day*. This will be the object of the next two chapters.

## **Chapter Five: Living Day-to-Day I: Creating the Local Community**

### **5.1 Introduction**

*Living day-to-day* encompasses the period from early childhood to preadolescence. This is a challenging, but often rewarding time when parents are sometimes stretched to their limits. As well as balancing careers and all the tasks related to taking care of a home and family, they must implement strategies and procure resources to augment their children's ability to learn and develop social skills, since they do not acquire these skills as readily as most children. During this period, a quest for meaning takes place which entails seeking a diagnosis, learning as much as possible about FAS/FAE, and creating networks of social support. As mothers pursue this quest they become advocates. I have divided the material which covers the stage of living day-to-day between two chapters. These chapters cover the same time period in the lives of these families, but a detailed treatment of the process of *becoming advocates* requires a separate chapter. Chapter Five, Living Day-to-Day I: The Local Community, will deal with the ways in which parents strive to meet their children's needs at the level of the local community which includes the family. Chapter Six, Living Day-to-Day II: Becoming Advocates, will discuss how mothers create a support network for themselves in the FAE Community, and, through this process, become advocates for their children.

### **5.2 Creating the Local Community**

The major process outlined in this chapter is *creating the local community*. The local community acts as a support system for the child. The smallest unit of this community is the family, which must adapt to the needs of the child. One mother of several FAS/FAE children described the process of discovering strategies to manage the child within the family, and teaching them to other family members as the first step in advocacy (Lutke, 1993). When children reach a certain age and want to take part in activities with friends outside the family, they begin to venture into the local community. The "local community" in this thesis has a specific meaning. Rather than the usual sense of a geographically bounded neighbourhood, and the people who live and work within it, it is here defined as a social network of adults who act as role models: coaches and instructors, teachers, and neighbours; as well as same-age peers. Parents rely on these people to provide a safe and enriching environment for their children. In fact, they try to duplicate the safety and protection of the home in external relationships that will be beneficial to the child.

The following section deals with the strategies parents use to extend the safety and security of the family into the local community. The sub-processes of *creating the local community* are: *sharing the load of parenting*, and *creating and maintaining protective environments*. *Sharing the load of parenting* is comprised of two strategies: *communicating and cooperating*, and *spelling each other off*. *Creating and maintaining protective environments* requires the following strategies: *directing and monitoring the child's activities*, and *establishing a peer group and finding role models*.

### **5.2.1 Sharing the Load of Parenting**

The importance of the family carries over to *living day-to-day* from the stage of *living as a family*. The family is the smallest unit of the local community which parents create as a refuge for the child. The cohesive family unit provides the firm foundation from which to strategise, organise and coordinate activities, The guiding force of the family is a strong marriage. Since the family, based on a well established marital relationship, plays such an important role, it is worth taking a close look at the the relationships of the parents in this study, and examining the previous research on adoptive parents.<sup>1</sup>

This discussion begins with an examination of the factors which create strong marriages, which, in turn, lead to resilient families. The family acts as a support system which is a protective environment for the children, and a basis for more extensive social networks. Next, parents' efforts to extend this safe environment outside the family will be presented. The difficulties which must be overcome in order to accomplish this task will be enumerated, and examples will be given to illustrate each point. Then, some typical activities which the children enjoy are outlined with examples. These are primarily sports or artistic endeavours.

### **5.2.2 Marital Relationships of Adoptive Parents**

The family provides the firm ground on which efforts to help the child are based. Families, in turn, are themselves built around strong marriages. While the mothers in this study with preteen children were eager to discuss their current problems, their descriptions of the efforts their families have made over the years to adapt to their children's needs show persistence, cooperation, tolerance, stamina and love. Josie and Bob, the couple with adult children, are still together, and the single mother with adult children, Paula, is now married to a long time friend who was present and supportive through the most difficult times.

That parents have remained together, despite their difficulties, may be related to the fact that these couples were married for several years before they adopted their children.

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<sup>1</sup> Paula is the only single mother in the study. She received much support from both friends and her own family.

All were in their thirties and forties at the time of adoption, were highly motivated to become parents, and had previous parenting experience or received formal and informal instruction in parenting. Chapter Four showed that having survived the more or less difficult period of *adjusting*, these families were in a strong position to carry out the tasks of *living as a family*. The successful completion of that stage has reinforced the integrity of these families. Research has found that most married adoptive parents have very strong marriages, and a low divorce rate, and are well-educated and financially stable (Daly and Sobol, 1994 ; Saskatchewan Social Services, 1980). The couples in this study fit this profile.

While participants were not asked directly about their marriages, in response to questions about emotional and practical support mothers were consistent in naming their husbands as major sources of support. Likewise, when researchers questioned parents of children with disabilities, who have behaviour problems similar to those of children with FAE they found that, “[s]pousal support emerged as the most important resource variable for families of children with externalizing behaviors”<sup>2</sup> (Suarez and Baker, 1997: 379). It was more important than “global” or general social support from all other sources (Ibid.).<sup>3</sup>

Mothers mentioned two important factors which they feel have kept their marriages intact and helped their families withstand crises. I have named these *spelling each other off* and *communicating and cooperating*. *Spelling each other off* is the sharing of household and parenting tasks, so that one spouse does not become exhausted. *Communicating and cooperating* refers to spouses supporting each other and solving problems together. By combining these strategies, parents are able to weather the day-to-day stresses and frequent crises which arise.

Debbie:

So we do a lot of splitting the girls up. And we work that out. And it's not without its conflicts. I mean this is just ...I'm not sure why we've survived and other people haven't. Like I know some, I know better parents than us that haven't been able to hold their marriage together over this.

We personally know five or six families whose marriages have been dissolved over this issue.

So I don't know if we're dysfunctional or what we are, crazy? But we seem to be able to rally. I know [there have] been

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<sup>2</sup> “Externalizing behaviours” include behaviour that is aggressive, hyperactive, or defiant.

<sup>3</sup> Social support can include practical help, emotional support, and advice or information (Suarez and Baker, 1997).

times when things have been really really bad but we always seem to rally.

The majority of these people are flexible in their expectations about parenting, and are willing to try different approaches. In Chapter Six we will see that this ingenuity is carried over into other areas, such as finding methods to assist their children in learning academic and life skills.

### 5.2.3 Spelling Each Other Off

Debbie:

It's really hard work, it's very stressful. But fortunately we've been able to hang in there, 'cause if we didn't have each other...we spell each other off.

Debbie's term "spelling each other off" refers to taking turns, so that neither she nor her husband become completely exhausted. The following discusses the different arrangements which the families have made to share household duties.

Mothers carried most of the burden in *adjusting* --especially on an emotional level--since such a great emphasis was placed by all parties on their bonding with the children. During the stage of *living as a family*, by taking part in activities together as a family, the responsibility for raising the children is shared for a time by both parents and older siblings. Consequently, some pressure was taken off the mothers. In the stage of *living day-to-day*, in all cases, some of the responsibility for parenting was shouldered by fathers.

When asked about the types of work performed by themselves and their husbands (and other children where relevant) during the stages of *living as a family* and *living day-to-day*, mothers were generally satisfied with the sharing of tasks. The majority of women shouldered the largest proportion of responsibility for child care and running the household while the children were living at home. Similarly, other researchers have found that

... mothers [of children with disabilities], in comparison with fathers, spent significantly more hours helping the child and conducting household tasks, provided the child with more types of support, was more involved in organisations, and worked less hours" (Heller, Hsieh, and Rowitz, 1997: 409)...[and] "...the mother's degree of paid employment had no significant impact on the time devoted to the family member with a disability. (Ibid., 413)

In the study by Heller and colleagues (1997), mothers reported significantly more caregiving burden than fathers. While I did not pose questions about caregiver burden, the

mothers in my study described the work of raising their children as a partnership between themselves and their husbands. Since Heller et al. found that when fathers had higher levels of caregiving, mothers did not reduce their share, they suggested that “in addition to being affected by characteristics of the child and their own time demands, the time both parents spent helping was also determined by shared values regarding family caregiving responsibilities”(p. 414).

Josie clearly outlined the sharing of household work between her and her husband when the boys were young.

Josie:

Yeah, [from the time Mark] was three to five and a half, both Bob and I were working full time but our house was about half a kilometre from the hospital where we were both based. We had a local person come into the house and stay with the boys during the day. We came home at lunch. No, we were equal, equal caregivers.

This couple shared housework and child rearing tasks equally, switching roles to adapt to changing circumstances.

Josie:

The next stage in our life when Mark was six and seven, I went back to school, we were in Puerto Rico then. I was a graduate student. And Bob stayed home and took care of the boys, so he was much more of a primary caregiver at that time.

The other couples divided their duties into separate domains. Fathers tended to spend time with their children in activities outside the home like sports, woodworking, and taking them back and forth to lessons. As well as performing some of these same tasks, most of the work within the home such as housework and child care was undertaken by the mothers.

Feminist anthropologist Michelle Rosaldo (Rosaldo and Lamphere eds., 1974) places the key of gender asymmetry in the universal division between domestic and public spheres. Women are primarily bound to domestic activities and the home due to the fact that they bear and nurture children. Men, on the other hand, are connected to the public realm of economic, political, and ritual activity. Men and women, then, have their own realms or ‘worlds’ in which they have autonomy (from Mukhopadhyay and Higgins, 1988). While in some societies these relations are seen as complementary, when domestic labour is devalued, power relations between men and women become asymmetrical. While these concepts have been found less useful cross-culturally than in Western societies (Ibid.), I believe they are applicable to the present study.



Debbie describes how she and John share a lot of the effort needed to supervise the girls. She, however, takes on most of the household duties.

Debbie:

We make it up as we go along. What he's good at I guess, I'm not as good at. What he likes to do with Kate for example ...we have to make sure that one of us is able to take her on at any point; one-to-one, if necessary. So like Saturday before she went to [summer] camp she was just wired because she was afraid, stressed out and excited about going, but she was literally bouncing off the walls.

So he says, 'get your fishing rod, we're going.' So they drive all the way to [a resort] on Saturday. They went fishing and they went swimming and he just wore her out. They got in the car and went. So that one-to-one doing something that she wanted to do, that she liked doing was absolutely the right thing to do. And he'll take her to the shop at work and they'll build something or he'll take her out, that's no problem. So he does a lot of that with her. Ringette, he does ringette with her, six o'clock in the morning.

The day-to-day stuff around the house I'm better at. So I do the bedtime routines and the morning. ... because she's got no reason to go to school she's...it's such a horrible place for her, until recently it was. Literally, [our home care worker] and I, we dressed Kate in the fall. Getting her through that transition of getting her out of bed, getting through the door, getting to school. That process of taking her toward something she doesn't want to do, like bathing. Bathing is not something she's interested in. I'm better at moving her through the process. It may take me forty-five minutes to get her through the shower ... and sometimes I don't have the energy, but I can work her through that and get her there.

So I do a lot of the bedtime stuff. And what we do at bedtime is one of us has to, there's a routine we follow. Becky will follow the routine, she needs the routine, but she'll take herself through it now. And as long as she can follow the routine she can manage and her light will go off at a reasonable time and she'll put herself to sleep. As long as we make sure she's got everything that she needs to get through that. She can almost do it independently.

Kate, on the other hand, if someone doesn't make sure she stays in her room and in bed, would be up all night. Her internal clock is nonexistent. And she's not interested in following a routine. So, what we do is work her through the routine, get her into bed. So it's down to the detail of going in, shutting the light off, taking her glasses off her face, tucking her in one more time, going back three or four times,

and sitting outside the door some nights if necessary. But always one of us has to sit by her door. [We have always had to do this, but] ... now she's older [twelve] we do that 'till 10:30, 11:00 at night. So we don't even have an evening together, ever. So those things around the house I'm better at.

John concurs with Debbie's analysis.

John:

Well, with Kate, it's usually which one of us is strong enough to handle her that day. And I can take her out for the whole day and we can have a great time as long as its a goal directed activity it's easy. Like she wants to go do something...[he describes the same example Debbie describes above]. But when I got her home I had to turn her over to Debbie because I'd been on all day. Debbie, now you've got to put her to bed. Because transition times are really rough with her. Making the transition, especially to bed and out of bed are the worst times and Debbie has to do those. Because I just don't have the patience.

...And if it's an inside thing it usually ends up being Debbie who does it and if it's an outside thing it usually ends up being me. I take one of the kids out onto the driveway and play basketball....So it's an outside activity I do it. An inside activity Debbie does it. Or I'll take one of the kids down to watch a movie and explain the movie to them. But normally it's getting to the point where we have to split the kids up, so it's one of us with each one.

As Debbie said earlier, she does many of the household duties, apart from cleaning. Here, John explains that cleaning the house takes second place to caring for the girls. Both he and Debbie tackle this job when they can squeeze it in.

John:

As far as sharing the housework goes it's whichever of us decides they can't stand the mess first. Because the housework comes a distant second to looking after the kids. Like I can't stand looking at this shower any longer so I'm going to take the scrub brush and the Tilex into the shower with me, and I've got to scrub the shower and then I have my shower. And stuff like that. Sometimes the house doesn't get as clean as it should be because, or could be because all of the time and energy goes into the kids.

Eva delineates the arrangements which she and her husband have made.

Eva:

Well, actually when we adopted Cameron I took a year off. So I had the first year off, and I only worked half time after that. So I still did most of the housework. Larry is, as far as picking the kids up and dropping them off, you know he's always done his fair share of that. That's not a problem at all, as long as I remind him, set up a schedule.

And so generally I worked half time. I went back to three quarter time after the kids went to school. It was really tough even half time because Tim went to special needs preschool and I had to take him to a sitter out of the area. And Cameron was in school and he went to a different sitter.

We spent a lot of time going to...just name a specialist and we've seen them, speech therapist, physiotherapist, psychologist, plastic surgeons, ear nose and throat specialist. So I did the bulk of that mainly because I had the more flexible job. I could set my hours somewhat depending on whether we were doing workshops and stuff.

So we just did a lot of adjusting. And we used child care too. We tried to have child care in the home and it never worked out. We had three or four bad experiences. So a lot of it was just shifting around. And we tried to be off [work] when the kids were off [school].

Susan's older children, at home until recently, were very helpful in the day-to-day care of James.

Susan:

I find scouting is a day-to-day, ongoing...you just have to know what badges you are working on and how could this fit into that. My husband will help him work on badge work. And so will the other kids actually. So all of them are involved in that. Scott and James will watch videos together. Kelly will watch videos with him too, but different kinds. She likes Walt Disney videos so she'll watch Walt Disney with him. Scott will most likely rent a wrestling movie.

Taking turns even sitting beside him at the table sometimes. You need to do that. But just to make sure that the food gets to him. You specifically have to say to him, 'Do you want beans?' or 'Here are the beans.' because he hasn't necessarily been aware that we're having beans. Sometimes it's just a little reminder that says [whispers] 'Try your serviette, it works, that's why they invented them.' The other

kids are really good about that. And we all take turns reading bedtime stories to him. I found very early on that reading to him in the evening was a real relaxant.

This example illustrates how this family fits guiding James in his social and life skills into their normal routine.

James enjoys the time he spends in his father's workshop. Here, Susan explains the special relationship her son and his father share. Note that she hints that some tension sometimes arises because of the different parenting styles of Susan and her husband.

Susan:

My husband is very mechanical and so he would work out in the shop, and James, having fine motor skills that are very good, my husband lets him play out in the shop. And I'm not sure what kind of arrangement they have, because I'm not sure I could live with this arrangement but it doesn't affect me. He appears to be able to use any tools that he wants, use anything that he finds in fact. Most of which is not returned, and some of which is broken, and so on down the line. And my husband, actually [an] admirable trait in this man, seems to be able to deal with that much better truly than I could. I allow James a lot of freedom, but I'm also trying to teach him responsibility for returning things. And if you accidentally break something you have to notify people and it has to be replaced or something like this. So, but they have this arrangement, okay. And if [ what James is making] doesn't work out often he will be frustrated and angry, and then my husband will say, 'I'm sorry but you have to go to the house now.' [laughs] Some punishment that is, 'You can deal with this dear.' No, that's not true. He probably would deal with it.

Paula, a single mother, had to be everything to her boys. She worked and relied on friends and family, and after school childcare to assist her in looking after her sons. Research on parents of special needs children indicates that single mothers use more services than two parent families, but this does not mean that they are under more stress (Floyd and Gallagher, 1997). Paula did not recall this as a time of hardship, since both Brad and Jason were not having major problems in school, and their home life was relatively tranquil compared to the traumatic times which were to follow. Much of her time was taken up caring for Brad who was a sickly child. This caused friction between the boys.

Paula:

He was always pretty jealous of Brad. I think because Brad was kind of a sickly allergic kid and needed a lot of attention.

I think it was really hard for Jason when Brad came along. He was a bit rough with Brad. I know I tended to sort of minimise it but Brad's foster grandma was very unhappy with it, with the way Jason treated Brad.

In fact, Paula did not recall too many details about childhood activities, since she was still caught up in the turbulent flow of her sons' troubled lives. She was concerned with explaining what she was currently going through.

In order to coordinate the sharing of tasks it is necessary to have clear lines of communication, and the willingness of family members to cooperate. This will be discussed next.

#### **5.2.4 Communicating and Cooperating**

Josie and Bob placed a high value on communicating clearly and often about how they handled their sons when they were children. They also cooperated in implementing strategies they devised to both discipline their sons and help Mark with his school work.

K: And you said that you and Bob strategised a lot.

J: Daily.

K: Could you tell me how you did that ?

J: Well I think in the early years it was more conversation, trying to understand Mark, trying to understand his behaviour. He was just off the normal, as we perceived normal. So trying to understand it. Some regarding discipline, and how to try and have the same discipline and same approach with both boys. But they approach things really differently. So they could really have had a different style of parenting and discipline but we wanted to treat them the same. That was always a strain too, trying to be fair and equal with them even though they were different.

...so we just constantly talked. How would you handle this? How should we respond to that? How could we behave so it did come across as being equal to both ?

And then I would say that our strategizing increased as Mark got into school. Because then we had another set of problems to deal with; the expectations of the school.

In retrospect, Josie admits that she and her husband should perhaps have been more flexible in their parenting style. However, at the time, they were acting on their experiences and the advice they had been given in order to do the best job possible. Josie mentions that the transition to school brought "another set of problems" into the home.

Indeed, she and her son had perhaps the most negative, and ultimately damaging, relationship with the school system.

Eva and Larry also cooperate in parenting responsibilities such as disciplining their sons.

Eva:

Well, discipline, just whoever's buttons he pushes disciplines him usually. But it's never really been a big issue. I don't always agree with the way Larry handles things. He probably doesn't always agree with the way I handle things.

We don't argue about that in front of the kids. So whatever one parent does, the other one never contradicts, at least in front of the kids. That sort of thing. Usually they get sent to their room or moved.

This couple takes a very relaxed approach to parenting. They are by no means lenient, but are confident in their roles, are not afraid to admit mistakes, and change their approach when necessary.

The delicate balance of these arrangements of *sharing the load of parenting* is highlighted by what happens when they break down because the husband is absent. Both Josie and Susan have experienced problems coping when their husbands were away from home for extended periods. Bob often worked overseas and Carl continues to work in the city for several weeks each year. Susan and Carl require the income from this employment to keep the farm going, and to help finance their children's education (they currently have two in university).

Josie explains how she had trouble maintaining the same level of discipline with the boys when her husband was away.

Josie:

Well, yeah Bob was often, he travelled a fair amount. And every time he did we'd have trouble. I think the boys, both of them, simply knew that there was less enforcement around. And they know they could push me to a greater extent than they could when the two of us were there. We were a stronger force together. So they always pulled stuff when I was alone. The bigger they got the more they pulled...and I think they just instinctively knew that it was a more vulnerable time and they could get away with more. So they did.

Susan summed up her situation very effectively.

Susan:

It's James and I, end of the discussion. Well, with my husband being away in the winter--He teaches [at a college in the city]--and he's gone [a week at a time]. It's ten weeks maximum, it's [through] October to April or end of March. I find that very hard.

Parenting James alone, especially now that both her older children are away at university, is a very intense and tiring experience for his mother. She explained that her husband's absence cuts her off from some community activities, which supply an important source of respite and support. In this rural area, many events are geared to families only. According to Susan, their definition of a family is mother, father and children. Susan described how their community is very traditional, with most occasions seeing the men involved in one activity and the women in another. If Dad was present at a function, James could go off with him for a while "with the men," and give his mother time to visit with her female friends. If she goes without her husband, Susan has to keep her eyes on James at all times, and she finds it easier and safer to just stay at home.

### **5.3 Creating and Maintaining Protective Environments**

*Creating and maintaining protective environments* includes the following strategies: *directing and monitoring the child's activities*, and *establishing a peer group and finding adult role models*.

#### **5.3.1 Directing and Monitoring the Child's Activities**

Chapter One presented a summary of the children's medical and behavioural problems. The most pressing and time consuming issue for the parents of school aged children, was the need to monitor the children's safety. Children with FAS/FAE are often fearless, and do not think through the consequences of their actions. A related problem, is the children's lack of social awareness which is so impoverished that parents refer to their children as "socially disabled." The lack of social awareness, and need for heightened vigilance has led to a specific type of parenting, especially regarding the need for strict discipline. Outsiders may see this as overly restrictive. Parents may feel awkward in this role until they realise the danger of loosening their hold after a few close calls.

Eva explains how she gives directions to her children.

Eva:

Actually we talk too much. We've got to learn not to talk as much and just react. Like, 'Go to your room!' not, 'Well, next time...'

Eva's reference to not talking so much refers to her children's difficulty in understanding complex language, and comprehending the consequences of their actions. These issues will be examined further in Chapter Seven. By giving orders to her children rather than explaining things, Eva says she is taking a directive approach. This method, with its focus on parental control, which has the children's safety in mind, is followed by the parents of the preteen children in this study. This approach is derived from research, and the experience of parents. Debbie paints the most effective picture of directive parenting.

Debbie:

The type of parenting we have to use with these kids has been called 'Attila the Hun parenting,' meaning that the rules are hard and fast and there's no grey. It's black and white and that's what they need [it to be] because they can't think through the abstract or the grey [areas]. So you need to have, 'This is the rule, if you're on this side of it you do this, and if you're on that side of it you do that.' Now it seems harsh to us[for whom] independence means you negotiate the grey, and they can't do that. In fact for many of them that's so stressful for them to have to do that, and they make mistakes, right? And then we smack 'em for being [pause] for making[pause] I mean society [says] 'You're stealing you know, whack!, into jail.' Our expectations are beyond their ability.

Eva explains how this approach works in the classroom for her son, Tim, with the help of a classroom aide.

Eva:

You've got to be really directive, 'I want you to do this. I want you to sit here, go out for recess, sit here.' And then don't allow them too much free time or get out of that little box. You have to allow them free time, but a lot of times that box is there to protect them from the outside world, as opposed to keeping them in. A lot of it...kids can be really cruel...kids have a hard time when they're different.

Eva's image of "the little box" in which she keeps her son is not only very evocative, it is rather controversial. It certainly points out some of the contentious issues which arise when discipline or other areas dealing with changing or managing behaviour are addressed. Furthermore, this passage highlights one of the important components of this protective environment which parents create: shielding the child from the harm and "bad influences" of the outside world. A discussion of these issues will ensue in Chapter Seven, and will be extended in Chapter Eight. While this directive approach is effective during childhood, it may become increasingly difficult as the children enter their teen



years. As we shall see in Chapter Seven this is precisely what happened in the case of Josie and Bob's son Mark. In addition, Paula gave her son Jason more freedom and responsibility, which brought its own problems for his younger brother. Her experience was similar to that of Josie and Bob in that she insisted that her son obey house rules, which caused him to rebel and leave home in his early teens.

Susan illustrates the way her nine-year-old son puts himself in danger and needs almost constant supervision.

Susan:

James is still young enough that you still have to be aware of where he is all of the time, following constantly to make sure that he is safe. Now that he's a little bit older we're still having to do that, but it's not the minute by minute. You only have to check every 20 minutes now. ...I have found that working with other fetal alcohol children [that] they're often quite noisy children, so you can always hear where they are. So we always know where he is if he's in the house, but if he's outside then you need to check. Well, we have a slough and we have a dugout you know, and there's machinery.

Stade (1995) also found that vigilance is an issue which places stress on the child's parents because it takes so much time and energy, and carries on after most children are more independent.

Debbie is becoming concerned about the fact that her daughters are reaching an age where they will no longer be able to participate in summer camps and sports groups which have a broad age range (for instance, from five to ten). In such groups, adults keep a watchful eye for the safety and well-being of the children. In activities for older children, the focus is on teaching responsibility and leadership skills. Her girls are ill equipped for such a challenge.

Debbie:

...if an IQ of 70 or 75 is how you're going to measure it, then they're not mentally retarded by that criteria: but they certainly are. They are toddlers and preschoolers in preadolescent bodies, and their ability to adapt to the environment is functioning at that level.

She describes her twelve-year-old daughter, Kate, as functioning at about a five-year-old level in some situations.

Debbie:

... it varies, and it's circumstantial, but I guess overall if we

just keep in the back of our brain that her response may be of a much younger age, then we're better off. Because we put the protections in place and safety measures there, [suitable for a five-year-old] and then we feel like we're okay in terms of supervision and structure and that kind of thing.

Parenting these children requires an approach which may seem counter-intuitive, providing less freedom as they grow older. Researchers have documented a similar pattern in parents of children with mental retardation:

Having a child with mental retardation is a non-normative event and raising a child with a disability is a non-normative process. Examining caregiving from a developmental perspective that takes into account the degree to which the life stage tasks faced by families are normative, Farber (1975) theorized that as the child moves towards adulthood, caregiving becomes less normative and more taxing. This discrepancy between what is normative and non-normative is exacerbated if the child is highly dependent. As the child reaches adolescence and adulthood, parents may still be involved in parenting tasks more typical in families with younger children. Also, the stage of launching out of the home is delayed or may not occur, as offspring with mental retardation often continue to live with elderly parents. Two contrasting theories emanating from the research on caregiving for elderly relatives, can also offer a framework for understanding family adaptation over the life span. The 'wear and tear' hypothesis predicts that the long-term caregiving demands and accumulation of stressors results in depletion of physical and psychological resources (Johnson and Catalano, 1983). On the other hand, the 'adaptational' hypothesis (Townsend, Noelker, Deimling, and Bass, 1989) suggests better adjustment to the caregiving role over time. (Haverman, van Berkum, Reijnders, and Heller, 1997: 417)

From the parents' stories, it seems that they both adapt to this altered parenting role, and may become "worn out" at times. This is especially so, if they do not receive the support they need through formal services such as respite care. As Haverman et al. make clear,

The present study points to the important role of formal service provision throughout the life span in helping families cope with raising a child with [disabilities]. Use of formal services predicted both lower caregiving time demands and lower perceived burden of parents...this finding may indicate that formal services can reduce the time that families provide care and help provide emotional support to families. It also suggests that in the Netherlands [where the study was carried out] the service system is perceived by families to be helpful in addressing the support needs of the families who use the services. (p. 423)

Unfortunately, as will be outlined in Chapter Six, the parents' needs are often unmet by the formal service systems such as medicine and education.

### **5.3.2 Establishing a peer group and finding role models**

All children reach the stage of venturing out beyond the family, which can cause some anxiety for their parents. Alcohol-affected children, however, lag behind their peers in organisational skills, being able to handle responsibility, and awareness of personal safety, which makes this period especially difficult. Their parents spend much time and energy cultivating a peer group for their children which they deem suitable. They observe other children, evaluate them for positive traits, and select those role models who can be a "good influence" on their children. Another important source of role models are older siblings, coaches, teachers, and the parents themselves. While most parents monitor their children's friends and activities for negative influences, I contend that this particular group of parents have designed and implemented a carefully crafted plan which they carry out in a deliberate manner. This is serious business.

From their parents', and society's, point of view, these children seem to lack "common sense" appropriate for their age. However, when one examines their choice of activities, these children sometimes exhibit "extraordinary senses;" abilities that differ from the norm, sometimes in very positive ways. Nevertheless, these children require special handling which can take a lot of emotional and physical energy.

John provides an example of the time and energy needed to arrange an activity for his younger daughter and her friends, because she lacks the organisational abilities of most children her age. Both his daughters require constant supervision when they are together, and much guidance when they are apart.

John:

And you can't leave them on their own. So it's always doing something with them. So yesterday, Becky went to the pool with some kids. But the organising of that ... because she phoned up some kids to go to the pool. So you have to coach her into these things like checking the pool times and making sure everyone's got the money to go. All these little sequencing steps that you or I would think about if we were organising a bunch of people to go somewhere. So even intervening to get her to do that is a pressure situation [for me]. Then you drive them to the pool, and then you have to be around the phone in case they call. You don't notice [how much time and energy it takes] until you sit down and think, 'What have I done today?' I've looked after the children. 'What else have you done?' I've looked after the children. All day, all day I've looked after the children.

In cultivating a peer group parents build a network of support for their children, and put much time and effort into keeping it intact to enable their children to “stay connected.” Eva points out the careful strategizing of parents in both monitoring their children and carefully cultivating a peer group, and what happens when this is not successful.

Eva:

How do we best work with this child? Certainly the directive approach and structure, as long as he has that structure. Where we lost it with Cameron this year, and where I see where the difficulties surfaced, were I thought we had him too structured. ...we do music, dance,...So I set two days aside where I'll be home and he can play with his friends. That was where the trouble started. There were shoplifting and other things. He had all of this unstructured time. He's playing with other kids that have difficulty making those connections themselves. You get them together, nobody's checking on their every movement: bingo!

So as long as he's playing with basically regular kids, and we're trying to create that. And when I give him a timeframe, I'll say 'you have to be home at [a certain time] and if I happen to drive over there to check, you'd better be there.' So that's allowing them some freedom but within [limits] ...So that's something that does help with fetal alcohol kids.

He's been good in the summer but basically because I control who his friends are, who he plays with. You get brain damaged kids, ..I mean Tim's brain damaged, and I'm assuming that Cameron's brain damaged, call it what you like. These other kids [they play with in the neighbourhood] have severe behaviour problems. So these are the kids that are playing together [if left to their own devices] and they're just feeding off each other. And I stopped structuring all his time. I pulled back and allowed him free time, and as soon as I did that's when he got into problems. So it really reinforces--whether he's ever diagnosed or not-- if I give him too much unstructured [time], if I don't treat him like he's got this damage [he could get into real trouble].

Rather than dwelling on their academic achievement, parents' most pressing concern is their children's social and emotional development that lags behind their peers. These children's inability to understand social rules and expectations can be traced in part to neurological damage, often very subtle, which was caused by insults to their prenatal environment and, in some cases, their early home environment. The types and causes of neurological damage were discussed in Chapter Two. The damaging effects of abuse and neglect are discussed in Chapters Six and Seven. These children are characterised by their parents as “socially disabled.”

Eva:

A child or person with fetal alcohol syndrome or fetal alcohol effects is definitely disabled because there's permanent brain damage and it affects how they function in society. And also because, although there's no one way of describing FAE or FAS one of the common themes is that children and people with FAS/FAE don't learn by consequence and that is the way our society functions. So that if you do this and you do this and this happens. So if you can't make those connections, if you're never able to make those connections you are extremely disabled within our society. In a different society they may not be considered disabled.

She elaborates.

Eva:

But anyways, he's quite lacking in social skills and that explains why he has trouble making really good friends, he doesn't know how to do that. He doesn't pick up on social cues at all. You just about need to take a hammer and a two-by-four and get his attention, and then often you have to draw the connections for him. That's where he's losing, he's not making the connections. And [this behaviour is] really subtle. Unless you live with this child, you know, initially you're not going to pick it up.

This social awkwardness usually leads to some degree of marginalisation, and without some intervention from parents or other adults, these children have the potential to become quite socially isolated. In *Falling Apart* this process of marginalisation which can lead to mental illness, and the descent into a life of crime will be discussed. Debbie and John strive to keep Kate involved in activities she enjoys since she is perhaps the most socially isolated of the children in this study.

Debbie:

We have to really program our older daughter's time so a lot of our effort goes into providing structure and programming for her. And we're fortunate because there's two of us and we can spell each other off. Because she's really socially disconnected now from a lot of her peers, a lot of other social contacts. So lots of times we're it for her.

John describes he and Debbie are providing Kate with both a peer group and structured supervision at school.

John:

We pay ..[kids at] lunch hour to get somebody to look after Kate. And she got onto it with a couple of girls at the end of the year... these kids have been so good to her, and they played soccer and they went out on the swings, and they included her. It was like having a paid peer group. She'd have done anything for these kids, and they'd wave to her on the street, and just amazing the things they were doing with her. They were providing her with that structure and supervision.

He goes on to explain why behaviour modification does not work:

So [the school administration said she's doing really well with the supervision, let's cut the supervision off now, we don't need to do this anymore. We've fixed her!...[and the first day without supervision she left the school yard and got into trouble]... of course Kate is being blamed. And the school comes down on Kate because of her behaviour. Hadn't she learned how to behave at lunch? No, because that's not what we're teaching her, what we're trying to do. We're not trying to teach her how to behave at lunch, we're providing her with lunch supervision. ...That's like giving crutches to a crippled kid and when the kid can walk really well with the crutches saying, 'The crutches work, take the crutches away. You stupid kid, you fell down. Didn't you learn anything? Come on, get up and walk!'

One must recognise that social isolation is not a foregone conclusion for these children. While much of the previous literature has portrayed them as friendless and socially isolated (cf. the description of Adam in *The Broken Cord*) (Dorris, 1989), this is not true in all cases as Debbie points out.

Debbie:

Our younger daughter's much more social so we're finding now that she's like a typical eleven-year-old, she's not as mature as ... well how mature is an eleven-year-old? [laughs] But it's obvious with her that the gap has significantly widened between her and her peers. She mimics behaviour. She's doing really well socially. You would say she's doing really well [but] most of the time she doesn't have a clue what's going on, she's mimicking. So the telephone rings off the hook for Becky, Becky goes to parties, Becky on and on and on. But she's still very socially connected so she's

actually doing a lot of activities with her peers now. So we're into the driving like any other parent of a preteen. We're into the driving routine, here there and everywhere kind of thing with a van full of kids. So that's basically our situation at this point.

These children certainly need help in establishing and maintaining friendships due to their lack of finesse in social situations, but this can be accomplished under certain conditions. Parents identified several important factors which resulted in positive situations for their children. First, other children who have known the children with FAE since early childhood--old school friends, cousins, long-term neighbours--become accustomed to their different behaviour, and accept them unconditionally.

For example, Debbie discusses Kate.

Debbie:

She'd been with the same group of kids all the way through school and had, especially in grade three, ... no disruptive behaviour. Well, minimal shall I say. It was manageable and the other kids were supportive, 'Oh Kate, don't do that!', kind of thing. The kids knew her, weren't afraid of her, accepted her. She was a disabled child and they accepted her.

Her younger daughter, Becky, has a close circle of friends who take turns spending time with her.

Debbie:

Oh yeah they're just so socially adept and they're...you talk to her friends and they're just on another plane from her. And they're very caring and they're...like part of the reason she's doing so well is she cycles through a group of about five of them. And they're kind of, they're a gang, so she doesn't wear one out. You know, she goes around the circuit and that way they kind of, she goes to the same spots that they do and all that. And so she's staying connected and surviving.

Second, parents must educate people about the safety issues discussed earlier, so that they maintain careful vigilance. Next, what are perceived by others as unusual and unpredictable behaviours--such as complete withdrawal or violent outbursts--are usually the consequences of specific actions or social contexts. Parents must explain that by controlling these factors, these behaviours can often be prevented. For instance, the aggressive behaviour shown by Kate and James, or withdrawal behaviour and crying, is often a direct result of these children becoming extremely frustrated by a situation they do

not comprehend. This can include anything from struggling with a math problem to misunderstanding a joke.

Debbie:

[At a summer camp for learning disabled children] ...she's not attention deficit if...the environment is appropriate.[Debbie read log book entries that showed the following pattern]. And you could see when they were doing addition and subtraction [everything was fine] and they started getting behaviours at some point, and you could just see it: they'd moved into division and multiplication. She couldn't do it, or she had a bit more difficulty with it. And her response to again being presented with material that was beyond her capability was to precipitate behaviours.

And,

Eva:

[When he's playing], Tim sometimes thinks the other kids are laughing at him and they may or may not be. He doesn't always pick up on it and that really upsets him.

Kate and her sister have fewer behaviour problems when they are kept apart.

Debbie:

Everything from the poking and the swearing to the hitting, the stealing from her. And sometimes it just gets out of hand. She really is very aggressive sometimes. Kate's 160 pounds now, and what may start out as a minor thing to her [ends with her] actually doing physical damage to her sister. So our behavioural management strategies have gone from sort of being like this [trying to get them to get along together]... to [trying to] keep them apart, or keep Kate from the situation.

An important strategy used by the mothers is avoiding the use of labels when they converse with others, which could lead to the stigmatisation or stereotyping of their children. Mothers are thereby facilitating social interaction with their peers, and minimising the risk of marginalisation. For instance, parents carefully filter the information they provide to adult role models regarding their children's diagnosis, supplying only what they think is necessary for that particular situation. Additionally, in these situations, rather than using the FAE label, parents use descriptors which acknowledge the most critical issue at hand, or use more familiar terms. For example: "learning disabled," "you may see some unusual behaviour," "he has hearing problems,"



and “he has attention deficit disorder.” This strategy maximises the success of the interactions, while minimising the possibility of stigma or misunderstanding.

Debbie and John have found this tactic successful.

Debbie:

With ringette this year John just went in the first day and at the end of the introductory thing the coach said, ‘Now do the parents have anything they need to say?’ And John said he just took a deep breath and stepped forward and said, ‘Well, my daughter is severely learning disabled and you may see some behaviours that you’ll wonder about. And what you need to know is it’s okay and that this [being in ringette] is really good for her.’ And they said, ‘Like what kinds of behaviours?’ And he said ‘Well, you might see her acting really immaturely.’ He didn’t say she might whack somebody. It wasn’t likely to happen, but she might do some really strange things. And you know, they didn’t say ‘Get her out of here.’ They said, ‘How can we help?’ So we had this group of parents all winter long that saw some very strange things, that were really supportive and the kids were too. The kids caught on that she was different and they didn’t tease her.

Eva has had similar experiences.

Eva:

Also with Tim we’ve tapped into, there’s a special needs program...on Saturday mornings. He did that all year. Where he was matched with volunteers and he really liked that because he went swimming and he liked the extra attention and it was good. So we qualify to tap into things like Camp Easter Seal and a lot of other programs. To date we haven’t felt the need to do so. And the city’s been good. I don’t like to just drop them and not say anything. I usually just, well basically when I’m talking to people [about Tim] I say, ‘Well he’s speech and language delayed, he doesn’t understand what you’re saying. If you show him he’s fine.’ It’s never been an issue or a problem. Until it becomes one I’ll keep him in as many of the public services as possible.

She is grateful for the rest she receives in the summer when the boys can go to camp. Here Eva describes how she informs the counsellors about possible trouble before it can happen.

Eva:

One of the difficulties, ... Tim is [pause] he appears very normal in a lot of cases and can fall through the cracks. So I need to make sure ...they don't have to do a lot of extra work with him but just be aware of his presence [so] that he doesn't get himself into some difficulties like wandering off or not understanding what's happening. So I think he'll do fine. I've never sent Tim unless his brother's there. There's that connection. But as long as his brother's there he's fine. When they're away, Tim looks up to him then as his connection and he's okay with that. And actually they get along really well when Cameron faces the fact that there's nobody else to play with. Well, this is it then. They're typical siblings I think.

Debbie looks forward to the time when her oldest daughter can go to summer camp for special needs children. This is a rare few weeks of respite for her family. As we shall see in Chapter Six, this couple is coming to the end of their rope.

Debbie:

We concluded this last year. We've been out together in the evening twice in the last eighteen months. Because we just can't do that anymore if we don't have some kind of break. That's why [camp] is so great because I put her on the bus yesterday and I know she's going to be safe for the next month. They've got 39 kids and 40 staff I think if they count everybody. So I'm not going to worry about it. This is the only time I don't have to be on call. And all we really want to do is sleep.[laughs] That's what we did the last time we got respite, we went to bed at 10:30.

The children in this study have no severe physical disabilities, and some are even athletically gifted. This probably accounts for the fact that they have not faced barriers to mainstream recreation programs. Indeed, these young people have been provided with a very enriched environment. Their only obstacle to participation has been difficulty dealing with "unstructured" situations where they lacked someone to guide them through transitions, or could not comprehend sophisticated rules.

Eva:

Both the boys are very athletic, but Tim in particular. He rides his bike like you wouldn't believe. At three he could dribble a basketball and shoot regulation size baskets and get two out of four. So he's got that ability. [However], we tried him in soccer once, but the logistics of the game were just too... he

didn't know what was going on, he couldn't handle it.

While some of the children have above average athletic ability, this should not be surprising since most children with FAE do not have the physical difficulties of individuals with all the characteristics of fetal alcohol syndrome. Among this group of children, Kate and Mark seem to have had the most difficulty in this area, with coordination problems. Participation in sports was used as a corrective measure. What is consistent in all the children is the enjoyment of artistic endeavours, from creative writing to music, dance and drawing. Some show exceptional creative talent for children their age. This finding has been reported elsewhere in the literature (Kleinfeld and Wescott, eds., 1993; Raymond, 1997).

Eva has encouraged her sons to participate in music and dance lessons. Again, however, Tim is unable to cope without individual attention or close supervision.

Eva:

Cameron [has done] hoop dancing. [He] stayed in hoop dancing for a year and that was really good. Tim is also, this year he was in Jazz in a regular class. And he performed in a recital at [an] auditorium. And he really enjoyed that. And his teacher came out a couple of times and asked if we're going to put him in next year. She really enjoyed working with him. So he'll be in that next year. He's also very musical. Music really speaks to him, drums particularly so I got Tim into drumming. But again, Tim couldn't cope. It was too unstructured. It's not like in a classroom, like he didn't have an aide. And when I'd take him he was just so agitated. I would pick him up when he'd finished he'd thoroughly enjoyed it but there was no-one to say, 'Tim, sit here, do this, it's your turn.' None of that, so his stress level was very high.

Debbie talks about Becky's creative talents.

Debbie:

And she's artistic. She gets a lot of points for her artistic ability. She goes into that other part of her brain, and comes out with stuff ...[even] people that don't know her or know she's disabled comment. So she really has a strength there.

We got her into ballet at four and a half because she wanted to go. There was some motivation there. And she is functioning at a peer level with the kids her age. So they all passed grade three [ballet] together. Her and her friend, who started at four and a half too, got the same mark in ballet.

Nevertheless, the theme of overcoming inadequate social skills to keep her daughter “connected” arises again. Debbie is convinced that ballet has not only been of great benefit to her daughter, but similar activities would be helpful to other children with fetal alcohol effects.

Debbie:

It's a little bit difficult for her right now because some of the kids are changing in the classes and socially it's really hard for her because a lot of these kids in ballet are, for lack of a better word, “stuck up.” So she doesn't get it, right. So she's finding that hard. But we're really working hard with the director of the school to keep her plugged in and really encourage her because I think this is...I don't know how much that physical...Like to pass grade three ballet you have to be very, you have to know where all your body parts are, you have to do things really well. I mean it's very focused. But it's patterning, you know, same steps. And I don't know how much that's contributing to her stability and her emotional strength. But I suspect it has a lot to do with it. The discipline, the routine, the patterning. I don't know what's going on in there but I do believe that. And other parents that I know that have their kids in dance say ‘Yeah, it did make a difference to my kid to do that.’ So I think that's an important clue with these kids.

Susan admires her son's ability to observe objects and reproduce them in detail in his drawings. This is especially surprising given his frequent lack of awareness of his surroundings, which often gets him into trouble or puts him in danger.

Susan:

S: Well, the observation part, he can see things that I've never seen in my whole life. He's been really good for our family. If he saw a butterfly he can redraw it. He almost has a picture in his head. I would not question what that butterfly looked like. My memory would never be as good as his....about what it looked like. And he could actually put that down on paper, and bring that picture back to recall on another occasion to do that again. He may not be aware of 17 cars that are out there behind, beside that butterfly, but that particular item... he will have that in detail.

K: I guess he likes to do a lot of art work?

S: We have suitcases full!

It will become evident in Chapter Seven, when discussing the shortcomings of the

school system, that the children's enjoyment of and ability in creative pursuits should be more fully reflected in the curriculum. Parents are hopeful that their children may even be able to find some occupation where they can put their talents to work.

#### **5.4 Summary**

This chapter has outlined the ways in which parents nurture their children within the family, and create social support for their children in the local community. The next chapter will discuss how parents gather knowledge and create support for themselves in the FAS/FAE community.

## Chapter Six: Living Day-to-Day II: Becoming Advocates

### 6.1 Introduction

While the previous chapter discussed how parents strive to meet their children's needs within the family and local community, in this chapter our view broadens to include the national and international arenas. The focus in this chapter is on the process which mothers undergo in *becoming advocates*. There are two interacting strategies which mothers use in order to secure both the knowledge and social support<sup>1</sup> which they say are necessary to enable them to do the work of advocacy. I have labelled these strategies *navigating the systems* and *creating the FAS/FAE community*. By *navigating the systems* parents concentrate on learning how to negotiate the complex bureaucracies of the health care, education, social service, and justice systems. Their quest is primarily for diagnosis, services, and treatments but useful contacts are established which may become part of a support network (the FAS/FAE community). Furthermore, parents gain confidence during this quest.

*Creating the FAS/FAE community* is the means by which parents set up support networks for themselves. The primary focus is on establishing emotional and practical support, but information is exchanged among community members which can be useful in negotiating the bureaucracies listed above. While parents begin by soliciting information and advice from professionals, they find that little is forthcoming. In reaction to the inadequate treatment of their children, and their inability to obtain useful information from professionals, parents seek out the support of others in the same situation as themselves and thereby join the FAS/FAE community.

This social support, however, must include information which can be incorporated into strategies to help them manage or obtain services for their children. According to the participants information is useless without a social context within which to interpret it, and empathy is impotent without knowledge which can inform parents about strategies to help their children, or which may enable them to change the status quo. *Navigating the systems* and *creating the FAS/FAE community* should be seen as interdependent. Parents gather the information and strength they need to venture into the systems from the FAS/FAE community. It is important to point out that this is a gradual process, with the role of advocate being an extension of the role of mother. Mothers, then, do not set out to "become advocates." Advocacy work grows naturally out of the work of mothering. Similarly, the successful strategies they have found both to manage

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<sup>1</sup> See Chapter Three, n.9.

their children's behaviour and help them learn academic and life skills at home, were described as "coming naturally" or unconsciously. In fact, they are derived from years of careful observation and trial and error. These women become advocates in the context of a search for meaning. The nature of this search is discussed next.

## 6.2 The Quest for Meaning

Many of the participants have spoken of putting the pieces of a puzzle together with reference to trying to understand their children. This occurs through a journey or quest. As Josie says, "...the FAE diagnosis was made by us in our own search for information." In other words, they made it outside and without the help of the medical system. The diagnosis itself is only a stage in a longer process of seeking understanding. It is only part of a larger picture, and is certainly not an end in itself.

The shape of this puzzle is constantly shifting. It is dynamic rather than static since children develop, new research is undertaken, and societal attitudes toward and knowledge about FAS/FAE change. The mothers themselves become transformed as the quest proceeds since they undergo a gradual learning process which leads to empowerment. This transformation is described in terms of before and after. Their responses can be summarised as: "Then, I didn't know better. Now I would handle the situation differently." This quest is undertaken by *navigating the systems*.

The mothers described themselves as being at different points in this learning process which they said lasts a lifetime. None of them called themselves experts about FAS/FAE, but agreed that parents have expert knowledge about their own children. The academic in the group said that professionals could be "experts" if they balanced their professional knowledge with direct work with children and their families. The other mothers said that most FAS/FAE "experts" are out of touch with the reality of the mothers' experiences, and are not interested in their views.

Parents make a journey from inexperienced novices to seasoned advocates. They do not walk this road alone; their fellow travellers are other parents, professionals who are sympathetic to their cause, and others who are drawn into this community. Parents change dramatically in both their attitudes toward professionals and interactions with them, as they become informed about both academic and clinical research and the workings of "the systems," and gain the self-confidence to make themselves heard. At the outset, they already own a rich body of intuitive knowledge, and years of experience "in the trenches" have made them "experts" on their own children (although they are loath to use this word). By the time they have spent several years fighting for the needs of their children, parents are aware of changes which need to be made within each system and lobby both the government and the public to implement such changes.

Parents begin to search for information to help them understand their children, when these children begin to act differently from other children their age. The quest for

diagnosis results from the parents' own sense of the existence of a problem. Observing their children and realising that they have problems that need addressing are the first two steps taken by parents to find the meaning of their children's behaviour. Mothers had an intuitive sense that there was "something wrong with" or "something different about" their children. This realisation came about at different points in time for each family. For Josie, Eva and Susan, whose difficult time in adjusting has been discussed, the discovery that their children were outside developmental and behavioural norms came very early.<sup>2</sup>

Debbie recalls that daycare workers voiced their concerns about their oldest daughter to her and John when Kate was in preschool.

Debbie: "I remember when she was in preschool, the daycare workers were saying, 'You know, there's just something here.'"

Oh yeah, we got our first phone call with Kate when she was four and a half. That's when we began to suspect something was wrong. Actually up until then we didn't have a clue. You know, really experienced day care workers had spotted this, and we really valued what they had to say. They said, 'You know, there's just something here.'

Her parents took no action at the time.

Once parents suspect that these behavioural differences may be caused by FAS or FAE their search intensifies, and they seek validation of their suspicions in a diagnosis. They must also discover services which will assist their children, and they gradually take on the roles of education and advocacy.

### 6.3 Navigating the Systems

There are three sequential phases which people must pass through in order to become familiar with and function within each system: *entering the system*, *learning the language and the rules*, and *playing the game*.

#### 6.3.1 Entering the System

*Entering the system* is the first step parents must take. Parents come into contact with professionals when they seek treatment for their children's medical or behavioural problems, or, most commonly, when the child encounters difficulties when he or she enters school. Parents reported that these experiences ranged from beneficial to unsatisfactory.

The first contact is often a family doctor. In any case, a professional of some sort is consulted to obtain a diagnosis or name to attach to this behaviour. The meaning of a diagnosis for each participant will be discussed later. Typically, parents saw several individuals before contacting someone who was in a position to assess their child.

Waiting periods of a year were not uncommon to see specialists, especially in child

<sup>2</sup> See Chapter Four, *Becoming a Family*.



psychiatry and psychology. This is not an unusual situation in the urban centres of Saskatchewan. A recent study found that,

[t]he total number of registered clients (includes children from other health districts) in the SDH Mental Health Services Early Childhood program (less than 6 years) in 1995/96 was 328. This group made up 11% of all children and youth service clients. The waiting period for service varies depending on the urgency of the problem. Emergency cases are seen within 24 to 48 hours. High risk and urgent cases have a waiting period of five to six months. (SDH, 1997: 140)

The same waiting time is in effect for children up to age 13 (Ibid.).

In Kate's case, by the age of eight her aggressive and other inappropriate behaviours were increasing and her parents took her for counselling. The counsellor advised her parents that Kate was probably suffering from attachment disorder, owing to the neglect she had suffered as an infant and the lack of physical stimulation in her foster home. Older children who have spent many years in institutions or a series of foster homes, who may have been abused and neglected, may never bond with a parent since they "have learned that trust and attachment lead only to painful separation, and so may be wary of forming new relationships" (Triseliotis, Shireman and Hundleby, 1997: 236). They may display emotional detachment, superficial attachments to others, and aggressive behaviour (Ibid.). Kate began regular counselling sessions. Soon, however, a chance encounter at an adoptive parents conference suggested, in her parents' view, a more disturbing cause for Kate's problems, and led Debbie to search for answers in another direction.

At this point, parents view the information they need as beyond their comprehension, lying within the realm of professionals. This body of knowledge is filtered through the perspective of each professional who comes into contact with the parents. They act as gatekeepers to the academic research and clinical treatments which may be available. Parents have little input into decisions regarding treatments or educational settings for their children. They trust that these doctors, teachers and counsellors will act in the best interests of their children, and therefore defer to the professional expertise of these individuals. Debbie presents a typical example.

Debbie:

She said right to my face...when I told her she needed structure, a structured environment, 'Well you need to know I run an open classroom Mrs. \_\_\_\_\_.' And that was the end of that. And of course Kate bombed out in her class. She didn't ... have her needs met academically, but as a result they had lots of behaviour problems. When she doesn't have her needs met you get behaviour. So that's what happened to her

then. ... And me not understanding how important that was at the time, didn't push it any further. I thought she knew best. ... Were stupid at that time. We did end up moving schools. But we were just getting into this. I think we kind of trusted professionals at that point. We didn't know what a bad situation it was. We're a little bit smarter now.

The great imbalance of power in these initial relationships between mothers and professionals was evident in several recurrent themes: professionals dismissing the mothers' perspectives, practitioners blaming parents for their children's behaviour; and mothers feeling like they're on an emotional rollercoaster. The cumulative impact of these encounters leaves mothers feeling that they have not been validated, are inadequate, and even "crazy."

For instance, Susan was convinced that her son had ADD from the beginning, and suspected Fetal Alcohol Syndrome. She was aware of these disorders through her work at the preschool where she often refers children for psychological and other services.

Susan:

[The psychiatrist] saw James for one session and said, 'Have you considered the possibility that your son is attention deficit?' And I said, 'From the day I met him.'

James began to experience some problems relating to other children in preschool.

Susan:

He came for three years to the preschool,... he was not a sharer which is a big part of preschool. He mastered the basic things like the cutting and the painting and all those things with fine motor skills being a plus for him. Those things were easier. His comprehension was good, and you don't have to write anything in preschool ...I would say he was on a par with the other children who were going into kindergarten.

Only a few days into kindergarten, however, James, who has always been big for his age, was getting into trouble for hitting the other children. His mother had feared problems for the first time she saw the classroom and heard about this particular teacher from other parents.

Susan:

It was a very large class. The teacher had a reputation in our school for being very strict and ...didn't touch or hold children or like, kept a very large distance between herself and the children, which struck me as unusual in a kindergarten teacher

but anyway...And I went to the school and asked if it was possible for me to send an aide from my preschool, who was a lady that had been working with him, or could I come myself when school started and help James to settle in ... well the kindergarten room was...the walking spaces between the sand table was maybe a foot and a half to the water table and the block table ...and it was a maze, literally. And I realised this right away, as soon as I took James in the very first day and I thought, oh, this is not going to be a good place for James. He's not going to be able to handle this. There's too much stimulation here, ...it's closing in on him. He's terrified of small spaces. And she also doesn't open the windows. She has all the blinds pulled down all the time. One of the other mums who was with me that morning said, 'Oh aren't you opening the blinds?' And she said, 'Oh no I find they're too much of a distraction.' And I thought, 'Oh my gracious, here we are in kindergarten, and we might be distracted by the birds outside or something.' So I knew we were-- dark is not a good thing for James either--So I went to the principal and asked if it was possible for me to stay, and the word came back that same day that said 'no'. The teacher had forbidden me to do that .

Susan went straight to the principal, bypassing the teacher to make her request, but the principal sided with the teacher. The results were nothing short of disastrous.

Susan:

The upshot of that situation was that within seventeen days of kindergarten my son was expelled from school. His cumulative file says that he had premeditated --if you can picture that-- assaultive behaviour. 'Premeditated' would never be a word in my whole life that I would use for James. I mean these are instant children [ie. they act without thinking].

Susan is a teacher with two decades of experience. She also knows her son well and accurately predicted his reactions. Furthermore, she had spoken to other parents to obtain information about the teacher. Yet her judgment was ignored, to the detriment of James, his teacher and his classmates. While the arrangement of the classroom and the teacher's approach may have caused James to act out in this situation, physical aggression continues to be a problem for this boy. We will return to this issue in Chapter Seven.

Eva presents another example of professionals ignoring the wishes and opinions of parents. In the following quote she talks about her youngest son's experience with Ritalin, and her struggle with medical professionals to maintain control over his treatment.

Eva:

The school psychologist said, 'Maybe you want to have him checked for ADD.' So at that point I thought, well, it's come from two sources, so I went to [the doctor who had originally diagnosed Tim ] and I thought they would do some testing or something; he just gave me a prescription for Ritalin and told me to see my family doctor. Well, I wasn't pleased with that. So we put him on Ritalin for a while. And it was hard to tell if there was any improvement or not, but he wasn't a happy child anymore. We lost the happy Tim. So we took him off and I went to see my family doctor and I asked[him] for [a] referral to another paediatrician. So I went [to see her] and basically the same thing happened. Okay you weren't happy with Ritalin so they gave me Cylert....So we put him on that for a while and... I did some reading and there's some possibility of, I think, liver damage. If your child is on Cylert they need to have a test before they take it and, okay, well the doctor didn't tell me this. So when I'd done my reading I phoned her and questioned her on that and she said, 'Well I don't believe that to be true and that's why I didn't mention it.' And I thought well you don't have to believe it to be true, I'm the parent. But anyway I didn't say that. So I just took him off it altogether.

From the doctor's viewpoint this would be seen as "non-compliance," or refusing to cooperate with medical treatment, which has been the object of much research (Fogarty, 1997). Eva, however, felt that the doctor had not only put her son at risk, but had excluded her from the decision making process regarding this particular medication. This mother had done her own research, and armed with this knowledge, made the choice which she felt was best for Tim.

Debbie found that her children's objectionable behaviour is often blamed, especially by the schools, on "poor parenting," or some incident at home that may have upset the child. School personnel are the last to admit that their teaching approaches or classroom environment may be triggering problem behaviours.

Debbie:

But that's how it always starts out, that's how everybody approaches you, 'Is everything all right at home?' They assume that the behaviour has nothing to do with what they're doing with the child in the classroom or the school. Something's going on at home. And she's coming to school and not being able to cope in this environment. We had a new principal come in, and as I already told you, his first comment to me in September or early October, whenever the first big incident occurred, is, 'Is everything all right at home?' So that's where we started with him, ground zero. So there's this

inbred, ingrown, tunnel vision. The walls are up, they're entrenched in this thinking. And rightfully so I guess [in some cases]. A lot of kids are coming [from problem homes] but a lot of kids aren't. And a lot of kids are coming with another problem, and they're completely unwilling to look at that, even with Becky who has a diagnosis officially. That's how it always starts. It's insidious .

Other parents in this study confirmed this observation with similar experiences. Paula recalled one particularly awful experience when she and her boys sought counselling at a mental health clinic, in which her competence as a parent was put under the microscope.

Paula:

The other thing I'm thinking is, it isn't for lack of trying when families don't get help early. Because there really is very little help. You know, you go to your doctor and then you maybe go to [the mental health] clinic. An awful lot of what they have to say to you is, 'You're not parenting them right.' Or, it all ends up being [pause] One of the most humiliating things actually, and I agreed to it, was we had one interview with the fellow and they clearly were looking for families to use as training subjects. And he said, 'Would you be willing--our situation was interesting, we're all quite articulate-- to have our interview taped and have observers in another room [watch you and have it all] video taped? And they would watch it and comment on it and we would watch it. And I should have maybe suspected that I wasn't emotionally ready for that. I mean, I had to go through with it and I did. But it was absolutely devastating to hear those students commenting on what the parent's deficiencies were in this case, you know. And actually we didn't end up in a scheduled kind of therapy or treatment or any kind of thing after that. They just sort of never got back to us.

Parents, then, share similar experiences of being dismissed by professionals, and even blamed for precipitating their children's' behaviour. This leaves parents feeling inadequate.

Debbie:

Oh, all the time, all the time. You just, you think, oh my God, maybe it is me [that's doing something to cause this behaviour in the child]. Maybe it's something I'm doing wrong.' There's lots of self doubt with that .

Furthermore, professionals are seen as narrow-minded, coming at a problem from one perspective, not out of malice or even indifference but due to their training. Most of them

value their own professional expertise over the knowledge, experience, and wishes of parents. They take control of decision making regarding the children's needs.

Debbie:

So people who aren't professionals get it really quick. It's like professionals have this ingrained ...they're programmed. We hit that all the time. I can count on my one hand the number of professionals over the years who've actually sat back and said, 'How can I help?' As opposed to saying, 'This is what you should be doing. You're not doing this right'... So there's very few people that can actually listen and...do that kind of thing.

She realises that it is difficult to understand, unless they have been through the experience themselves.

Debbie:

And even when they do get it, it's really hard to understand unless you've done it and been there. I keep offering for them to take her home for the weekend, but nobody's taken me up on it! [laughs] If you survive, you'll know what to do next time!

Josie approached her son's psychiatrist for some advice about strategies to cope with Attention Deficit Disorder, but the information was not forthcoming.

Josie:

Well, I'd ask Dr. \_\_\_\_\_ for different things but I didn't get the answers I was looking for. He was a bit of a one treatment guy, that treatment being Ritalin. This set me out to research ADD and FAS, and I started to get more into the FAS.

His reluctance to explore other avenues led Josie to take matters into her own hands. Similarly, poor results from professionals led the other mothers to begin to trust their intuition, do some research, and begin to question the experts.

Susan was startled to find that information she wanted was literally out of her reach, or at least not amenable to photocopying, and certainly not meant to be removed from the premises.

Susan:

Upon looking at what little information I could find at [the hospital]... Do you know that they chain all their books to the

tables? [we both laugh] I mean we're talking about chains! I did get access to one of the books one day.

John relates a similar encounter, in which an employee of the school board was secretive about their policies.

John:

And at one point I was sitting in a meeting with \_\_\_\_\_ and she had this big black binder like that [ indicates thickness of about six inches with hands] full, and we're trying to talk about Fetal Alcohol Syndrome and what it says to do. We're citing things like *Fantastic Antone Succeeds* and she says, 'Well that's all anecdotal, it's not research...I have other information here that tells me differently' (she pats the binder). So I said, 'Can you share that with me?' She says, 'This is the property of the board of education. I'm not allowed to share it with you...but it tells me you're wrong.'

Through repeated interactions with doctors, teachers and others within the various systems, parents meet with frustration, and become critical of the these bureaucracies. Rather than giving up, however, they are motivated to take a more active search for information. Armed with this information, they gain the confidence to negotiate with, and even challenge professionals to gain the services they require to meet the needs of their children.

### 6.3.2 The Turning Point

Reading *The Broken Cord* (Dorris, 1989) was almost unanimously described as a turning point on this journey, leading parents in a more fruitful direction.

Josie:

I got very little information through health care or the social service system, mainly from books like *The Broken Cord*...We knew that there was 'something wrong' with him right from the adoption. But it was after reading *The Broken Cord* that it all started to make sense. After that 'bits and pieces,' an article here and there in magazines that someone suggested.

Mothers, then, by the time they discovered *The Broken Cord* knew a great deal about their children. They had come to the realization that these children were different, and this difference was causing them difficulty functioning in their social context. This information, however was chaotic, amorphous, meaningless. *The Broken Cord* provided

a new way of seeing things. It was a corrective lens which brought their experiences into sharp focus. This highly personalised account of a father raising his adopted son who had FAS resonated with the experiences of the mothers in this study. It brought the pieces of the puzzle into a meaningful picture which inspired mothers to increase their knowledge and understanding.

Furthermore, by bringing people with common experiences together in a shared understanding, *The Broken Cord* was the vehicle for creating what Frank (1995) calls a “moral community.” Members of moral communities have an obligation to reach out to one another based on a common need. The nature of moral communities will be explored in Chapter Eight.

### **6.3.3 The Diagnosis: Naming the Problem**

Language has a powerful influence over the lives of these families. If their child receives a diagnosis of Fetal Alcohol Syndrome or Fetal Alcohol Effects, mothers see this as a tool to both help others understand the problems their children face, and a key to opening the door to services. As discussed below and in Chapter Two, however, having FAS does not automatically make a child eligible for specific specialised services. These are currently made available on the basis of specific problems like speech and language delay, or intellectual disability. What a diagnosis of FAS or FAE should do is alert teachers, social workers and others that these children need careful periodic evaluation, so that supports may be put in place as early as possible. The importance of a diagnosis, then, cannot be overemphasised.

The diagnosis itself gives a name to this collection of difficulties. While they were unanimous about the necessity of specifically naming a syndrome so that researchers can keep track of cases, and to help compose accurate prevention messages, the label itself -- FAS, FAE, ARND--was not particularly relevant to their day-to-day lives. As discussed in Chapter Five, mothers are careful not to stigmatise their children by carelessly using the FAE label, and making the diagnosis known only to select individuals. Other, less detrimental terms are used to describe their children’s behaviour.

Mothers had varied reactions to the diagnosis itself; the meaning of their children’s diagnoses was highly personal. For Paula and Josie, even though the diagnosis of FAE came too late for meaningful interventions, they found naming their sons’ problems to be an immense relief.

Josie:

And so to have a clinical label of some kind and to realise that there is this organic cause is tremendously liberating. [Furthermore], as parent... it doesn’t matter for me which label was used, but for me it was very important to have a label so that what we were experiencing with Mark was seen



as a pathology, that there was a cause to it. There was some description of this pathology that had been experienced by others. There was some history of attempts to treat or support [it] in various ways. Part of it is being able to let go of blame as a parent, that we did not provoke this or cause it or exacerbate it, but there was actually an organic cause to it. So for me whether the typology changes or shifts is irrelevant. As long as it is recognised as something atypical and it deserves different attention. I think in the kind of health care system we have it's easier if we have things that have a label to them and then we can figure out what to do with them. If you just keep at the stage where we have a really difficult kid that's not very helpful.

and

Paula:

It seems to me in the last few years [FAS has] become quite a topic. You know, [my friend] is doing a thesis on it, that sort of thing. It just seems to me that it's finally got a sort of legitimacy. I remember [the counsellor] at SADAC [a support group for parents of teens with addiction problems]<sup>3</sup> really downplaying the whole thing. Like she talked about it and she was obviously aware of it, but her point was but it doesn't help to excuse, to compartmentalise a kid and say he's like this because he has Fetal Alcohol Syndrome. He probably does, but now we've got to deal with how is he going to live his life and how is he going to deal with his addiction. Don't use that as some kind of a crutch. I can remember having a sort of argument with her and saying, 'But it makes an enormous difference to me to understand what's happening.' I think her feeling was then you just write the kid off. Like you say, 'Okay, he's got Fetal Alcohol Syndrome so there's no hope. No wonder he's addicted and that's the end of the story.' Her point is we've got to work with kids and they've got to live with the reality of how they are, and you know, there's no point labelling them and it doesn't help. I remember saying, 'But it does help because I've been just agonising over how can this have happened. Whatever happened to this family that I had?' And to be able to see that this was something that was there from the beginning that you coped with in the ways that you did, and it's not such a surprise that this is what's happening now. And you can predict I guess, part of the trouble is the predictions are kind of negative especially as kids go through the teenage years. I think that [in the SADAC group] we did argue about that sort of thing, and what would be helpful to me as a parent. I think [the counsellor] said you've just got to get on with it, you can't say, 'Oh now I know it's FAE or FAS.'

K: But it did help you to know?

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<sup>3</sup> See Chapter Seven, Falling Apart and Reconnecting

P: Oh it takes away a whole lot of guilt, and you're really fighting a lot of that as a parent. It sort of says ... these are things that the child isn't doing deliberately, that he probably hasn't got control over. So you don't hate him so much for it too. It really made a big difference to me to start understanding it.

According to these participants, then, an official, formal diagnosis or "label" is extremely important for its ability to establish an organic cause for abnormal behaviour, which takes blame away from the parents. Susan and Eva, on the other hand, did not display any release of guilt after the diagnosis. In their pragmatic view, the diagnosis could lead to services for their children.

After learning about FAS/FAE at an adoptive parents conference, Debbie and John were quite sure that Kate had FAE, because of her birth mother's history of alcohol abuse, and Kate's behavioural and learning problems. Since Kate and Becky are biological sisters, John suggested that they should take both girls for an evaluation. They were referred to the Children's Clinic but had to wait about a year for an assessment. John and Debbie were surprised and disappointed that Kate did not meet the criteria for either FAS or FAE.

Debbie:

K: She's "suspected" ... FAS or FAE would you say?  
[Debbie had circled only "suspected" on the demographic profile]

D: She's FAE. We haven't been able to obtain a medical confirmation although she has been assessed because she does not have sufficient [physical characteristics].

Debbie was absolutely shocked to discover that Becky received an FAE diagnosis.

Debbie:

We didn't believe it until last year. I mean I didn't. John said, 'We've got to have her tested.' And I said, 'Oh she couldn't be, not my baby. It can't.' I didn't want to know. We were floored to find out that she had more of the physical characteristics. That was the darkest day of our lives when we found out she was affected too because she really had no behavioural problems, nothing to give us a clue. She was our darling little cherub, eh. Everybody loved her; she was so cute. [Of] course that's classic FAE, classic. They're charming, delightful. And she's still like that only she's not supposed to be like that anymore. She needs to be an eleven-year-old and functioning and having abstract thoughts, a thing that she can't do.

Debbie realises that it is difficult to make a diagnosis, especially when there is abuse and neglect in the child's background as was the case with Kate. When Kate was evaluated, she did not receive a diagnosis of FAE because she had none of the physical characteristics, only behavioural and learning problems. Debbie explains that a diagnosis would help explain these difficulties to others who often blame her parents for Kate's behaviour. However, she makes it clear that the lack of an official diagnosis does not hamper her parents' ability to handle her.

Debbie:

The difficulty with Kate is that a lot of her behavioural difficulties are quite likely the result of the severe neglect of her first eighteen months, so its very complicated with her. It doesn't really matter at this point because having a diagnosis of FAE matters to no one except us because we manage her as a disabled brain injured child. We wish other people would too. So, confirming the diagnosis, it's important that we know, at this point. And we would prefer that we had it confirmed. Because there's always that suspicion with people that we deal with, professionals that we deal with, 'Oh maybe that isn't what it is, etc.' But, treating her as a disabled brain injured child works, and not treating her as such doesn't. So, we do.

Before continuing with the stages of *learning the language and the rules*, and *playing the game*, I will present an overview of the nature of systems and, the people who work within them, as described by the participants in this study.

#### **6.3.4 The Nature of Systems**

The systems discussed by the participants include education, Social Services, justice and medicine. These systems are described in similar terms: they are inflexible, conservative, slow moving, and bureaucratic. Moreover, these organisations are large and unwieldy, and in some cases are portrayed as "dinosaurs" which have outlived their usefulness.

"The system" (of whatever kind) is oppressive to its employees, limiting both what they can do and say. It controls those it serves, by offering only a limited number of services or solutions. Furthermore, each system treats people as stereotypes (hysterical mother, FAS child etc.); it generalises rather than recognising them as individuals. Consequently, rather than assessing an individual's needs and tailoring a solution to meet these needs, it sticks people into pigeon holes, with each compartment having a specific solution taken from the standard list.

Many professionals, however, bravely venture outside their official roles in these

depersonalising organisations. By shedding their bureaucratic identities temporarily and acting “out of character” they are able to help parents negotiate the systems. According to parents, by “going out on a limb” and “cutting through the red tape,” these individuals are taking a political stance. By contradicting or criticising official policy they may be at risk of reprimands from their superiors. It was generally felt that many workers are “wonderful” people who go out of their way to help in small ways, despite toiling under ponderous workloads; it is the system that is “awful.”

There are those that are benign, “nice people” who prove to be unable to help. A minority of individuals, however, have “bought into” the system, following its rules and regulations to the letter. They are portrayed as almost inhuman, soulless machines going through the motions. These people show no caring because they are no longer able to, they have been dehumanised.

Those who are helpful and caring display empathy, and connect with their clients in a shared humanity. They understand the difficult and sometimes desperate position in which these parents find themselves. In contrast, those who deal with clients in an impersonal fashion are both alienated and alienating. They embody the characteristics of the systems in which they are enmeshed. The former may already be part of the FAS/FAE community or are prime candidates for “conversion.” Describing the absurdity of the proceedings she has witnessed over and over again in the juvenile justice system, Paula put it this way.

Paula:

There are so many court workers and John Howard society workers and you know, Social Services child care workers, it's a whole system in itself. And it kind of perpetuates itself. Sometimes like everybody is just in it, it's almost like a game that they're playing.

And some of those kids are little kids... and you think this is just a child, and this whole system is going on as if this is some sort of forty-year-old hardened criminal. And the kid doesn't understand the language. And the people in the stalls, the parents, can't hear what's going on and they're not involved. So who is this for? You guys are just talking away to each other in a language no one hears.

Here we see some of the tactics used by the justice system to distance and thus control “young offenders” and their families: the use of jargon, the exclusion of parents from decision making, and keeping the child uninformed. Similar tactics were described by parents as shortcomings of the other systems. The image of players of a game, or perhaps even pawns in a game, can be contrasted with the image of the professionals who “go out on a limb.” They too, realise that finding one's way around a bureaucracy is like

a game, but they want the parents to win. By surreptitiously slipping “inside information” to parents, and helping them negotiate or bypass the rules they can guarantee at least some degree of success. Often, helpful leads to other programs or organisations will be passed on. If this path leads to a dead end, parents still feel that they have been validated, and are given hope by the realisation that there are still people who care even in these impersonal organisations. They continue their search, fuelled by the hope that maybe the next doctor or counsellor will have the answer, and maybe they too will listen.

By the time parents reach a specialist who is in a position to diagnose their child they are eager to find an answer. They have already been struggling to manage these children at home, and had frustrating encounters with the school. At first they may be willing to “try anything” to make the situation better. In other words, parents have high expectations about the help these doctors, counsellors or special education teachers or consultants can provide. If one approach is unsuccessful, parents will try another. Dorris has described this as the stage of hopeful optimism:

When you're the parent of an FAS or FAE child, your goals change with the passing years. You start with seeking solutions: ideas and regimens to penetrate the fog that blocks your son's or daughter's ability to comprehend rules, retain information, or even be curious. You firmly believe--because it has to be true--that the answers are 'out there.' It's just a matter of locating them. (Dorris, 1994: 83)

Debbie describes how some parents at a conference she and Eva attended were rudely awakened from their optimism. She and Eva, on the other hand, came away feeling validated.

Debbie:

... I would say that ninety percent of the people in the room were just absolutely totally devastated by the conference results. They had come to find an answer [ie. a solution, a cure] and they were just devastated to find out that basically what they knew to be true was confirmed: the outcomes. Yeah, that is the outcome, what a surprise. And there was no answer.

But we didn't come away feeling that. I think we came away feeling sort of, well we both said, 'We're not crazy!' And that was really important to hear that once again I guess .

According to Debbie, she is motivated to keep going by both anger and desperation.

Debbie:

But mostly right now [that self doubt] is replaced by [anger, like on] one video I have where the parent on there [you can see] just the anger she has to professionals who didn't listen.

I found it interesting that Debbie did not relate an anecdote of a time when she responded in anger, but gave the example of another mother she had seen in a video who she was able to identify with. Clearly Debbie does not deny her own anger, but found it easier to describe the feelings of someone she could observe from the outside. It is only by reflecting on this image, that she is able to recognise and value her own feelings. Reflecting on the experiences of others, and relating those experiences to one's own situation are the process which take place within a "moral community" (Frank, 1995) such as a support group. Membership in such groups can be both can be both therapeutic and informative.

When I asked Debbie if she considered herself an expert on FAS/FAE, she smiled and said,

Debbie:

I would call myself a desperate mother. That's all I would call myself. There's far too many experts that think they know what's going on and I sure don't. But I'm desperate enough to keep looking and they're not. The real experts that I've met over the years are the ones that admit they don't know anything. The scary people are the ones that think they do, and then advertise themselves as experts in the field.

Mothers made it clear that most people are willing and eager to help, but may lack the knowledge or resources to do so. Several individuals were acknowledged as being particularly helpful, and knowledgeable about the issues surrounding FAS/FAE. Susan named both her son's teacher and counsellor; Eva spoke highly of Tim's resource teacher; and Debbie praised Kate's teachers [with one notable exception], a special education consultant, and several people who work in the adoption division of Social Services. The principal of her daughters' school, however, is the most outstanding example of someone who has gone above and beyond the call of duty.

Debbie:

We sent her back in good shape for grade six last year. Only this year we had a problem in that her teacher didn't really have any interests in these special needs kids. His hands were full and he wasn't really prepared to do anything for her. She tried really hard to show him that she could do the work. It was grade two or three work she was giving him and he wasn't satisfied with that. He gave her no positive feedback.

Some of the comments he had written on some of the work she tried to do in the fall are really, 'You can try harder. I know you can do it.'  
No, she can't do it.

And by October she was refusing to go to school, and she went into sort of an emotional collapse. She literally was classic refusal behaviour... She would lie under her bed in the morning in fetal position. That's when we hired our caregiver and I changed my hours. And that's when I went in and I said... to the principal 'Who's accountable if we lose this kid? We're not losing this kid because of anything that she's doing or we're doing, it's what you're doing. You don't want her here, you're not providing [for] her needs and she doesn't want to be here anymore.' And he decided that he was going to help. And he did a lot of things that he could in the fall but he had no resources to do that. So he's personally, I don't know, I think they have 390 kids in that school. I don't know how much time he personally invested in her last year. But it was substantial. It was not easy going but it was that kind of one-on-one. He came out...several mornings to our house and helped me get her, he drove her back to school... [Many of] her behaviours now are not associated with brain injury, they're associated with the negative feedback she keeps getting from the world. If she ever got it in her brain that we weren't completely committed to her going to school every day that would be it then. Why would you go to a place every day where you're treated like crap? She was trying to survive. So that was really morally difficult for us to keep sending her back to a place...but we knew in the long term if we didn't, if we tried home schooling, all those things we had to keep her connected[would be lost]. As tenuous as it was to that social community, we had to keep her connected.

### **6.3.5 Learning the Rules and Learning the Language**

As people within the justice system use terms that can alienate their clients and their families, so the medical and scientific communities encode their knowledge in arcane language. In order to understand this information, and to converse with professionals, mothers must become fluent in the vocabulary used by each particular system. *Learning the language* is the phase in which parents must learn the terminology or jargon of each system. The rules of the game must be discovered at the same time, so that this language can be put into useful action.

#### **6.3.5.1 Learning the Rules**

*Learning the rules* refers to discovering each system's organizational structure and rules and regulations, locating key players and determining their roles, and analysing the flow of communication within the system. This includes things such as finding out how

long one must wait for an appointment, which department to access for specific information, and which type of specialist can make a diagnosis. It also refers to how children are categorised as eligible or ineligible for a particular program or service.

The most significant rule of the board of education which parents quickly discover is the cut off point of 70 IQ points, which bestows the label of “mentally challenged” on a child, making them eligible for a classroom aide and other services. Tim is the only person this study who falls into that category (the rest are all considered to be of “normal” intelligence). He has definite disabilities, speech and language delay.

Eva:

He's been assessed on IQ tests as scoring 70, which is wonderful because that's the cut off point for services. I believe that the services we've obtained for Tim through the school system are not directly related to his diagnosis of FAE, but are related to his diagnosis as mentally challenged.

So, that's why...we've told them we don't want him tested again. I told the school board I don't want him tested. Because he could jump five IQ points, then he still can't survive in a regular classroom but technically he [wouldn't] qualify for any services. I also personally don't believe he's mentally challenged. I would not say that to the system because then we wouldn't get any services.

This somewhat arbitrary designation is seen as unfair by parents of children who do not meet this criterion.

Debbie:

We have friends whose kids have been tested below 70 and they won't have them retested because they're getting all the services for their kids. They're getting a teacher's associate, they're getting respite services, all kinds of things.

Eva, however, explains that the only “special” service she has used is a recreation program for Tim which is described in Chapter Five. Her family is also eligible for respite services, but Eva has never used them. She goes on to illustrate how the rules of the school board lead to a rigid pigeonholing of students.

Eva:

He didn't have an associate [aide] for kindergarten and we didn't necessarily want one, he didn't need it. In grade one we felt that he would need some help but they ... they couldn't do that within the confines they were working in, at least with the special needs consultant that we were working with. They couldn't do that because he's not autistic, he's not a danger to



the other kids and he could dress himself. Like they had this list of rules, so he didn't fit into any of those categories.

As well as a diagnosis of FAE, and a designation of "mentally challenged," the type of adoption, discussed in Chapter Two, has a direct impact on services, as does the children's ethnicity, as Native children with treaty status. While parents can negotiate with Social Services regarding funding, this process is often inconsistent and unpredictable. The current system creates "haves" and "have nots." This ties in with the necessity of an early diagnosis. If a child could be diagnosed early with FAE, then problems could be anticipated, and "reasonable" services planned for.

Parents viewed the diagnostic criteria themselves, as overly restrictive. This, like the categories of Social Services and the education system, led to the pigeonholing of children. Here Debbie captures the element of chance in obtaining a diagnosis by casting the process in the image of a slot machine.

Debbie:

D: ...I don't know if you're familiar with the diagnosis or how familiar you are--The Institute of Medicine in the States has been calling for a number of years to have them revised.

K: Yes, I've seen those. And they're not adopted anywhere that I know of. Some people are using them unofficially.

D: They're not using them here. They still have the rule of three: if you get three you get FAS; if you get two you get FAE; and if you get one, it's like Las Vegas; you don't get anything.

This quote also displays Debbie's knowledge of the latest research findings which have led to the proposal of new diagnostic criteria (Appendix A). Those children who are treaty status are eligible for coverage of their medical expenses. Parents, themselves, however must contact Indian Affairs to ensure that the child is on the band list. Indian Affairs then issues a "B number" which can be used as a treaty number. This ensures confidentiality for the child and birth family. This information, however, is not easy to come by.

Eva:

A lot of adoptive parents aren't aware of this and they don't give you any information. ... it's like pulling teeth to get this. They gave us a number, it was just a number they give over the phone, you don't get a piece of paper. So the first time we tried to use it, it was interesting. It was over here at the [pharmacy]. [The pharmacist] said it took her three days to track it down.

This assistance was especially important for those families with fewer financial resources. Eva was glad of this financial help, while Susan only took advantage of it for unusually large expenses such as her son's medication. She felt it both unnecessary and inappropriate to use James' Indian status to acquire things like eyeglasses when he was her child now, and it was part of her responsibility as a mother to pay for all her children's medical expenses, both her natural children and her adopted son.

Another important factor regarding access to services is the type of adoption (special, assisted and so on) which was discussed in Chapter Four. Children who were acquired by an assisted adoption are eligible for extra funding related to health problems or disabilities. This funding, however, is limited to conditions which existed at the time of the adoption. Eva discovered that Social Services is willing to rewrite these stipulations if she is willing to have an assessment done and submit a written report (for instance, to pay for tutoring for Cameron's learning disabilities). Funding is by no means guaranteed. A recent request for counselling for Cameron was met by a noncommittal, "We'll see what we can do."

#### **6.3.5.2 Learning the Language**

Through *learning the language* parents must gain competence in the local vocabulary in order to establish credibility with professionals by demonstrating that they "know what they're talking about" by knowing how to talk about it. Terminology and other information which is discovered at conferences or through newsletters may be used to learn the language. Other sources include magazine and journal articles, the Internet, and repeated visits to doctors and educators.<sup>4</sup> Once the language is mastered, it can be used by mothers to persuade professionals of the parents' point of view as they navigate the system.

The following are some examples of how mothers use words strategically to argue their case. First, they must advise people of the particular needs of their children. Then, they attempt to persuade professionals to use approaches which other parents have found helpful, or at least to change regimens which are not working for their children.

Eva explains how she describes FAS to people. Notice the careful use of terminology, and also the way she incorporates new knowledge into her vocabulary.

Eva:

And often when I'm trying to describe it to somebody who has never heard of it for example I don't use the term 'FAE' I use the term 'Alcohol Related Birth Defects.' So having said before that it's not a birth defect really, because I believe that's genetic, nevertheless if I'm explaining to somebody that's not familiar with it, I believe people understand what a birth defect

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<sup>4</sup> One source which I found particularly helpful, was the ABOUT information sheets, available at the Social Services office, outlining adoptions and the juvenile justice system.

is. So I always explain it as my son Tim, for example, and he's easier to explain because he's mentally challenged. But I'll say some of his behaviours and what's going on and why he's not functioning at normal level is because his birth mother drank and so he has alcohol related birth defects. How that manifests itself in Tim it's that he's speech and language delayed, he doesn't process language well. Since I came back from Seattle, I also always say, 'He has Alcohol Related Birth Defects because he's brain damaged. Brain damaged is he has organic brain damage.' And people say, 'Well what's organic?' 'Well, that's because something else was put in like the birth mom drank or whatever.'

Debbie outlines the reasons for her use of the term "brain injured" to describe FAS/FAE: first, this term is already in use, which makes it easier to communicate with professionals; second, it accurately describes the cause of the syndrome; third, using this framework may help find better treatments; and fourth; it may be a way to access new funding sources and services in the province.

Debbie:

Well, because of my health background I'm familiar with that term. And ... I think it was in the parent groups and things with people. And I know that to me, maybe it's partly I've been using it too, is a way to communicate with professionals. [Furthermore] to me it's a brain injury like any other. There are specific areas of the brain that have been damaged and injured in the same way, it just happens to have occurred prenatally. And when I talk to some, the people that I know that I'm connected with now, that I'm networking with, or that we're networking with around North America, they understand immediately when I say brain injury. They don't even bat an eye kind of thing. But it is a surprise to [other] people. To me, I think it's probably a bit of a key to opening the door because if you assume brain injury, [you wouldn't] continually try to change their behaviour [which] doesn't work. And the reason it doesn't work is because it's brain injury...[N]ot only is it not helping them it is making it worse. Because they continually get this negative feedback from the world that they are not good enough, it's their fault that that happened. In the case of my older daughter who lacks social skills and socialization, that's been her whole life. The world is just [pause] she's had this great big negative life experience.

And I guess one of the other things, the reasons why I think it's a good idea to use that locally is that we have...very few brain injury services. And some of the different parent groups and community groups out there have been lobbying for years for the brain injured. And SGI[Saskatchewan Government

Insurance] has just recently provided funds for a brain injury support program for their clients who've been injured in motor vehicle accidents. So out of that SGI is sort of getting the after school programming for these kids, and camps and things are developing out of that. But that other insuring body in the province that actually has some money realises that to invest in this is important to families so they can keep going. It's going to be of benefit to them. So as those programs develop I think people may say "Oh, gee it works for this brain injured person ..I guess the other point to that is, that group of brain injured client gets that service why can't these people [with FAE]?"

Here, she also says a diagnosis is important to the family but is not really useful, because it does not qualify Kate for services.

Debbie:

No, and it's not a big priority for us because it doesn't matter whether we have one or not. It doesn't qualify her for anything that she doesn't have now. It would help I think convince some people that it's a factor in her behaviour. Because everything is just so clouded by her behaviour that few people get past that.

Eva was dismayed by the lack of care which she thought the clinic which assessed her son would provide.

Eva:

And a diagnosis isn't any good without...The Children's Clinic already asked me if I want to have Tim reassessed at ten. Well, I don't have a problem doing that and I don't have a problem being involved in research. You need to have[pause]but they're not offering me anything at all. They're offering me absolutely nothing other than they can say at ten how he's developing. I can't do anything with that information. I don't need it. That's where a lot of the money is going in our health care system, is for assessment. Well, there's no point in assessing if you're not going to do anything with it. What difference does it make...what difference does it really make whether Tim is Fetal Alcohol Syndrome, whether he is mentally retarded, if I'm not going to do anything with that. I know that I have a child that isn't functioning like the other kids. I don't know how to fix it so what difference does it make what we call it? I mean I understand for research and other things they need to know, but in my life it didn't make any difference at all. It gives me [nothing to work with]. Now, it does now because my kids are brain damaged and I know that what I'm looking at works with people that are brain damaged.

Naming something as a syndrome is not useful if there is no treatment for it. Her last

sentence refers to the cognitive rehabilitation therapy she is using with Tim which she mentioned earlier. Understandably, mothers are primarily interested in information which they can apply to helping their children, rather than esoteric academic discussions. As Josie said earlier, it doesn't matter whether the typology (diagnostic criteria) changes, as long as children with this syndrome are recognised as needing special help.

Knowledge of the language and rules of each system, however, is no guarantee of clear lines of communication between parents and professionals. The following passage shows Susan's struggle to have her son diagnosed. She had gained sufficient knowledge of the rules relating to obtaining a diagnosis, and eligibility for programs. In addition, she had become well versed in medical terminology. She already had a thorough knowledge of the education system through her work as a teacher. At this point, Susan felt confident enough to voice her wishes to a child psychiatrist. Her confidence was fuelled by her knowledge of child development, and the goal of obtaining a diagnosis which would give her leverage in negotiating with the school to supply her son with a classroom aide.

Susan:

We worked very very hard my husband and I, well mostly me, but we worked really hard trying to get any kind of a diagnosis for James, to see if we could get extra funding. I was at one point willing to pay for an aide. But diagnosis is extremely difficult to get for anything. I saw four people before we were finally able to get to [the psychiatrist]. And he saw James for one session and said, 'Have you considered the possibility that your son is attention deficit?' And I said, 'From the day I met him.' And he said, 'I think we can help you and we'll get you into the attention deficit program.' He sat down with me and asked point blank questions mostly relating to the attention deficit at which point in time he said, 'I want you to think about medication. Let's see if it does any good.'

And I've thought we've come all this distance to be told that we need to put our son on Ritalin? Good grief! You know, there must be something more. And he said, 'I want to try that first.' And so we said 'Yes, okay, well we will do that if that's the first step.' And he said, 'It will make it easier to get your child back into school [he had been expelled from kindergarten]. It was [laughs]. He was right about that. So, James went on Ritalin. ...[W]e have stayed with it and we're also using this other medication as I told you. Then, because the school said that James was not eligible for any form of an aide or help whatsoever I went back to him and said, 'Well, this is all well and good. We're on the Ritalin and we're a little more focused and learning and so on but we need more.' And so he's [the psychiatrist] the one that did the FAE. In fact

he called James 'Fetal Alcohol Syndrome.' but he was just a little reluctant to sign that and sent us off to [the neurologist] who is ... at the university in paediatrics. And [the neurologist] absolutely refused to sign. Because James is too big, birthweight started out too big. He was ten pounds two ounces at birth. Fetal alcohol children are very tiny children usually, very small head circumference. James has a very large head circumference. So we went back to [the psychiatrist] and said, 'Look, if at all possible we really would like the Fetal Alcohol Syndrome diagnosis because we would like to have anything.' And he said, 'Look, if [the neurologist] won't sign the paper then I don't feel comfortable. But I will give you Fetal Alcohol Effect.'

Debbie points out an important issue that was not raised by the other parents. When the caregiver volunteered in Kate's classroom as an aide, the teacher did not use her productively.

Debbie:

...and our caregiver started going into the classroom two hours a day. The teacher didn't have a sniff what to do with her unfortunately. They ended up colouring together and doing all kinds of strange things. So it didn't really help that they had additional resources because the teacher didn't use her appropriately. Our caregiver, by the end of the year when she got her confidence up, around Easter time was doing things like just saying to the teacher, 'Give me that exam and I'll rewrite it for Kate.'

So she'd bring it home and her and I would work out a new exam and so instead of asking her to write essay type questions we'd take the same question and give her fill in the blanks, but we'd give her answers above. So she had to answer the question, she had to choose, she didn't have to retrieve the information, it was right there on the page.

So ... he basically said 'Well, okay.'

That was his attitude toward this. So she started getting marks like 80 and things like these on these little tests. And he didn't manage the other kids very well either. They would tease her about this and he never intervened.

#### **6.4 Playing the Game**

The strategies of *playing the game* are mobilised when mothers have already tried the official route unsuccessfully. From the mothers' point of view the official rules of the systems create barriers to services which must be overcome. *Playing the game* is built upon the foundation of the previous phases. The object of playing the game is to gain knowledge and services in the most efficient manner, often by disregarding the usual procedures and normal channels of communication. Parents use strategies such as

bending and dodging the rules, taking shortcuts to reach the key players, and “converting” people. Employees within the systems may perform these services on their clients’ behalf either voluntarily or at the request of the parents. In some cases, parents tried to avoid the conventional systems altogether.

By supplying critical information about their children’s needs to sympathetic administrative staff or professionals, facilitated by their expertise in shifting between lay and expert vocabularies, parents “convert” people. To “convert” someone to their perspective in the service of “spreading the word” about the FAS/FAE cause, parents pass on information they have gleaned from conferences, support groups and other sources to the potential convert. Once a person is converted, he or she may become part of the FAS/FAE community which is discussed later in this chapter.

As discussed earlier, the type of adoption slots families into specific funding categories. To access services or funding from outside these categories parents must first find an individual who is willing to listen to them, and then present a clear case.

Debbie’s daughters were not designated as assisted adoptions but she was able to access funding for a caregiver and a special needs summer camp for Kate through Social Services by an unofficial route.

Debbie:

We were not an assisted adoption because our children were not assessed as disabled when we adopted. There is no appeal process in the legislation for that. However, there are many people in Social Services that...wanted to be able to assist us because they knew we needed the assistance. So for the last eighteen months, two years we have had some financial support for a caregiver. And like for example, they’re paying for [summer camp]. And that's great. There’s a couple of people in Social Services that “get it” because they’re catching the failure of the community and the health and education systems to adequately support these children. The next place they land is the Social Services, and the next place they land [after that] is justice. So they’re catching the bag for the failure of the community to support these kids. And we feel that the appropriate supports should come in health and education. Education in particular because ... I mean that’s what kids do until they’re eighteen, they go to school.

Debbie has revealed a complex problem with the current systems which was common to other mothers’ concerns: the failure of the health and education systems to meet their children’s needs.

Mothers identified reasons for this failure: these systems are underfunded; funding is often concentrated in the wrong area; funding maintains large inefficient

bureaucracies which are difficult to change on a structural level; and, individuals within the systems are unable or unwilling to effect change. The mothers, therefore, see it as their duty to keep up the effort, to keep fighting for the cause by applying pressure on the systems to change. Earlier, Paula spoke of the youth justice system as a farce. She thinks resources could be more efficiently used in preventive measures in the health care system.

Paula:

Sometimes I think that whole young offenders system is working [pause] instead of a legal punitive sort of system what they need is some sort of mental health related system. I bet over half those kids, that they're really not, whatever they think they're doing with their programs isn't working because the kids aren't capable of responding to that kind of thing. I think it's trickling into the system. That's where I really do get frothy at the mouth. I think how can anybody make any good decisions if they've got sixty kids on their caseload anyway? You know, like most of those court workers have hundreds of kids. I know the one I dealt with...eight weeks behind, you never can get any immediate reaction to anything because you've got to put it off for two months 'till there's a court date and they've got to do a report.

What I think, if you did the right thing when they're twelve or thirteen, if you really do step in and find some kind of treatment program or maybe a residential program for a few years or something. Maybe you could fire all those court workers that dealt with them from age sixteen to twenty-five. You know, that probably in the long run you could save. And of course they don't know what to do but at least being aware of it is [something]. It's appalling how few group homes there are for instance for families if you've got a kid that can't live at home. There are no options, so they live on the street.

and

I guess it's partly because budgets are short term. If your department saves a certain amount in a two year period you look good, never mind that it costs you ten times as much five years from now, you're not having to deal with that. But I used to think who is going to change this because it's not, not that people maliciously keep the problem going. But the people who are in it are so immersed in it I don't think they're the ones that are going to say we need to handle this totally differently. You know, it's got to come from somewhere outside.

It was explained earlier in this chapter that mothers must monitor their children carefully. Parents could not emphasise strongly enough the importance of "tracking" the children. Tracking means observing and following their progress, whether on a new drug regimen, or in a new classroom. This task of monitoring their child's progress is reflected



in other areas of life that require a high level of vigilance. This begins with observing the child and discovering something is amiss, followed by watchfulness for the child's safety, and close monitoring of the child's peer group.

At the level of systems, the issue is accountability. John complained about the lack of good evaluations of programs run by the board of education, and their inability to prove to her that they had good outcomes because of poor record keeping. They explained that they did not have enough resources to do adequate follow-up on their clients.

Lack of information or follow-up from the clinic that diagnosed Becky started Debbie on the road to advocacy.

Debbie:

They don't follow children with FAE at the The Children's Clinic. So we haven't really had any other contact with them except to ask last year if they were going to be reconsidering their diagnostic criteria we would bring Kate back so we could try to get a confirmed diagnosis. They're not ready to do that yet.

[After Becky was diagnosed] basically the recommendation was, 'g'bye see you.' They didn't offer any other services for children that are FAE at the Children's Clinic. We asked for some brochures or some information. We had books already that we'd gotten but ...what we hadn't found was... any material to help explain it to the kids. They didn't have anything, there was no reference material, nothing. I asked for articles that would help us in parenting. Could they refer us to anything? Nothing. We got no referral for anything. The only suggestion was that we talk to [a special education consultant] who at the time was working on a manual for teachers, and thought maybe that information would be helpful to us as parents. But they themselves did not offer any services for parents.

That experience has been recounted to us over and over by parents here. I've talked to parents all over North America who've had that. You're basically told this: 'Your child has leukemia and is going to die, see you.' And that's the experience, we've all had that experience. And that was almost scarier than getting the diagnosis, was that they didn't have anything to offer, they couldn't refer us for any help or anything. We were basically on our own. We were fortunate because we had been connected for a long time to the adoptive parents' association. So we already had a built-in support network. So we basically just went back to the parents we knew who had affected kids.

Eva makes a similar appraisal.

Eva:

The Children's Clinic is touted as the place to go but all they do, you know, they just do assessment. They don't do any follow-up. They'll follow you up and assess you at the end of five years. But ...they don't do any training or any work with kids unless they're mentally challenged or have physical disabilities: they work with multiply handicapped children. But most of them are quite severely physically disabled as well. So they're not necessarily working with the FAE/FAS part... And the Disability Institute it seems they do more educational type stuff and prevention. And that's where the biggest push is in the province is: prevention. What's being missed is all the kids that are already born and have grown up to be adults that are suffering from FAE. I mean I'm all in favour of prevention, it's a hundred percent preventable. If you don't drink when you're pregnant then you won't produce a child with Fetal Alcohol Syndrome. But you've also got to look at the kids. It's a lifelong disability, it doesn't go away. It's brain damage.

Debbie and Eva's disappointment with The Children's Clinic is a symptom of a much larger problem. The clinic provides services such as speech and physical therapy to young children with multiple disabilities. Some of their staff are also dedicating time to conducting research on FAS/FAE in Saskatchewan. It must also be recognised that their client group is not exclusively comprised of people with FAS/FAE. Their resources must be directed at the most needy, the most disabled children. As well as a lack of funds to expand their services, this highlights the problem of lack of integration of services; the few services that are available are scattered across the province in different systems. The parents expect the people who diagnosed their children to be able to treat them as well in the same facility.

As discussed in Chapter Two, education and prevention have received the most attention in Saskatchewan. Prevention is crucial, but so are early intervention and long term services which change with the needs of the developing child to prevent so-called secondary disabilities such as mental health problems and criminal behaviour (Streissguth et al. 1996 ).

Davis (1994) gives the following advice to parents whose children do not meet the criterion for the designation as mentally challenged:

If the student does score high academically, then it may be advised that the classroom teacher and other staff members provide anecdotal records of the child's behaviour, over a specific period of time. If behaviours are consistently inappropriate and interfere with the student's ability to learn,

then he may be eligible for special education because of a Behaviour Disorder. (p. 40).

Eva, in Chapter Five, talked about the time she spent running her boys to appointments with various specialists. Parents of children with FAE often see many specialists (psychiatrists, counsellors, speech therapists, and sometimes surgeons) both during their search for a diagnosis, and in meeting their child's needs. Strauss et al. (1984) describe the devastating effects that such organisation of the medical system has on individuals with chronic illnesses and disabilities and their families. In one case of a multihandicapped child which they present, the parents were so exhausted by running their child to appointments that they were thinking of institutionalising him. Indeed, Strauss argues for a general and inclusive model in treating chronic illness, in which researchers and health care workers could concentrate on the common problems suffered by patients and their families, and then seek solutions to these problems of everyday living (1984). In Chapter Eight, I will discuss the similarities in this model and more recent ones such as Kleinman (1995) and the one derived from this study.

Debbie gives an example of how professionals and the medical system are conditioned to maintain the status quo.

Debbie:

I think a lot of the barriers there too, if you're a therapist or counsellor, you go looking for people to counsel or provide therapy to. And if the kid doesn't fit the mould, off they go. The services exist and if you can't recruit clients you go looking somewhere else and the ones that come and it doesn't work for them, it's not your problem. So the fact that we don't need the counselling services, then maybe we should be using those resources for something else for these kids. It's kind of difficult to bite off and chew for a lot of professionals. And I don't know what the drug companies would do if we took them off Ritalin.

The barriers, according to Debbie and Eva, start right at the top: at the level of the provincial government. Eva describes FAS as a "political football" because it has come to be seen in Saskatchewan as a Native issue because of the large number of children from this segment of the population who are affected. A recent study found that 80 percent of identified cases in this province were of Native ancestry (Habbick et al., 1996). Eva contends that because FAS/FAE is such a "hot potato" politicians were unwilling to make this issue a priority for fear of being branded as racist. Like the issues of pregnant women's autonomy discussed in Chapter One,

It has not been politically correct to discuss this phenomenon, said Dr. Michael Moffat, a pediatrician and head of the Department of Community Health sciences for the University of Manitoba. But early-learning problems can often lead to

trouble with the law when a child approaches adolescence. It's been one of those problems that hasn't been talked about as much as it should have been...there's been very little knowledge about the frequency of fetal alcohol syndrome in Canada. (Roberts, 1998: A6)

Also, in Saskatchewan,

Shirley LeClaire of Social Services' Family Service Bureau says, 'There's been a longstanding history in our community of not giving this the attention it needs. It's one of the areas where there's not a lot of attention paid, especially the fetal alcohol effects, because you don't have the physical attributes.' (Zakreski, 1998: A2)

The political climate has changed recently, partially in reaction to the public release of the results of the study mentioned below, and the larger House of Commons Report (1995), as well as the formation of the provincial coordinating committee which has been publicising this cause.

The effectiveness of a top down approach, however, is questionable. Debbie discusses a debate which she witnessed at a meeting of an advisory committee on Fetal Alcohol Syndrome. This is a multi-sector task force which has the mandate of coordinating efforts towards research, prevention and treatment in the different systems. While resources are available in other Canadian provinces, they seem to want to take the time and resources to reinvent the wheel.

Debbie:

We've ended up going to B.C. and elsewhere because there's some folks that sit on that advisory committee that were blocking them getting materials in from B.C. because they were, I don't know. Either they didn't believe [the accuracy of the material] or they were going to do it on their own or something. But to me it was absolutely the stupidest thing I've ever heard. One person at the one meeting I sat in on told the coordinating person for the province for FAS not to bother ordering materials in from B.C. The group out there didn't know what they were doing or something. And it was either that or nothing at that point. So I mean, this thing is just so political it just stinks, it just stinks.

There is a darker side to specialization, which creates a small number of "experts" in a specific field (i.e., FAS research and practice): it has the potential to create and maintain an FAS industry (Chafetz, 1996; Kleinman, 1995). Michael Dorris gives his impression of many of the experts in the United States:

The FAS Study Group was, at its founding core, a tight clique, a rarefied network that was its own best and most

trusted audience. Its charter members had associated with each other for years, had reacted in print to the minutiae of each other's research, had polished each other's finest points...As if to accentuate and preserve its exclusivity, past and present Poobahs communicated among themselves with a specialized idiom, as replete with banded acronyms as any Bureau of Indian Affairs subcommittee. Like a petty fiefdom ... the FAS Study Group seemed both jealous and contemptuous of less select entities. Theirs was a small pond whose residents had come to consider themselves very large indeed. With the notable exception of Ann Streissguth, who was accessible, generous with her time, interested in American Indian Material, and open-minded, I too often found the mavens of the fetal alcohol establishment to be arrogant, proprietary about their research, hard to approach, myopic and self-congratulatory. (p.228)

According to the mothers, the real action, however, is not to be found at the level of the coordinating committee but at the grass roots level. Eva is optimistic about changes which are happening at her sons' school, which Debbie's daughters also attend. It is her observation that adoptive parents are leading the way in advocacy efforts because they have the motivation and the resources to do so.

Eva:

But still as a parent you have to fight for all these services. If I don't go to the school and fight with them my kids aren't going to get services, if I'm not visible in the school. There are a number of kids in that school that should be getting services that aren't because there's nobody promoting them, their cause. It's not just done automatically. So it has to come from the parents. And the parents that it's coming from are the adoptive parents at this point. Part of that is because they're not [the biological parents]. I don't have any guilt issues about it. I can go and promote for my kids. I'm not guilty about whether I drank ... So I think [with] a lot of the other kids their parents aren't aware that there's a problem. So I think a lot of this is coming from the political climate, but adoptive parents have done a lot to promote the issue, because that goes with it. Those are the parents that I see right now are doing the lobbying, are doing the promoting, are doing the changing. And I believe at this school (I don't know what it's like at other schools) but they really want to promote, I think they really want to do the right thing. It hasn't always been perfect but I think they're really trying. They're really trying to get a handle on this. So I think it will become easier and easier.

Eva also explains how Debbie, her friend and fellow support group member, had "laid the groundwork" for Cameron at her sons' school since the staff were used to dealing with

her daughter Kate. Cameron would also be in the same classroom in which Kate had a successful experience the previous year.

Eva:

Having talked to some of the other parents [since] I didn't know either of the two teachers, [I found out that] there was quite a difference in the structure of the two grade sixes. So I went to the school before they planned the classes for next year and just said he needed to be in the more structured classroom and I explained why and said we're having him assessed for FAE. And Debbie had done some work ahead of me so there was a child with FAE last year in the class he's going into. So she's laid the groundwork hopefully, and she's really struggled because they don't have a diagnosis for their daughter, but she has severe behaviour problems. But they've laid the groundwork so it'll be easier for me. And [when I made this request] nobody batted an eye [or said] 'What's this?' I got the sense there was some understanding in the school. And so although he doesn't qualify for anything, the understanding [at the school] is that kids will do better with structure ... So he's definitely going to be in the [classroom] with the most structure and handle it from there.

To advocate, then, parents must come together and organise their efforts. As Josie described the situation, a critical mass of parents have come together at the school and been successful in lobbying for changes. They are able to do this through the use of the support network which they have created.<sup>5</sup>

### **6.5 The FAS/FAE Community**

The support network which parents create for themselves is the FAS/FAE community which may include researchers, support groups, other parents who are not members of such groups, and professionals who have been "converted." This term means that these professionals have seen the light, that they get the picture, or as Debbie says, they "get it;" to be converted is to understand the plight of parents raising children with FAS/FAE. It is through working directly with families, and through the direct action of parents that some professionals come to understand. As one person who runs FAS

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<sup>5</sup> Susan was quite taken aback when she read the outline of *Becoming Advocates*, because she did not realise that she had been "breaking the rules" to obtain services for James. She said that sometimes you have to be so single minded that you become blind to the needs of others. I spoke with her afterwards, and reassured her that I did not think the readers would interpret her actions as selfish, given the great needs of these children, and the limited choices presented by the school and health care systems at the present time. We both concluded that if parents keep demanding other choices that these systems would eventually have to change their rules.

workshops for professionals explains:

Currently, many parents claim that professionals usually have an 18 month learning curve before they “get the picture” and begin to understand children with FAS/E and their families. One of the primary goals of the FAS Family Resource Institute has been to offer education, information and intervention tools to service providers so that this learning curve can be shortened and appropriate crisis intervention plans can be implemented. (DeVries, 1997: 1)

Furthermore, these individuals must be dedicated to providing some form of meaningful assistance to affected families. Parents keep in contact with these people on a routine basis, and rely heavily on them in times of crisis. Over the years, some professionals may establish strong bonds with children and their parents. In one case, a counsellor became a family friend. Close friendships have been established among parents of affected children.

Parents feel free to discuss all issues around FAS/FAE without being judged or misunderstood by people in the FAS/FAE community. It is a safe haven where everyone speaks the same language or least a dialect of that language. Parents of affected children, however, share a special bond that allows them to communicate on an almost telepathic level. These parents’ experiences are so alike that they are not required to explain their children’s actions, or the frustrations they face in *navigating the systems*. Parents are not forced to legitimise their needs as they must when dealing with some professionals but are assured of empathy, encouragement and support when it is required.

When asked about their sources of support, apart from their husbands, who have already been discussed, the overwhelming answer from Debbie and Eva was the Adoptive Parents Association. Since parents had some contact with this group even before the adoption, long-term relationships were established. Eva is emphatic in her praise for this group.

Eva:

Well,... when we first started we always had speakers and stuff on different topics. Now, they didn’t always talk on fetal alcohol, because again that wasn’t known. The support came more from developing friendships with other people that had adopted, and ... you do things together with your kids, and you talk about things, and there’s that understanding. You don’t have to explain to people, ... about behaviour and different things because they just understand that. That’s the great thing...you don’t have to go in and say, “Well, this is what’s going on and this is what’s happening,” and people look at you like you’re crazy. Because they look at the kids and they look, I mean, Cameron has a cleft lip and palate but

otherwise he looks normal, you know. You look at Tim, and he looks normal. So, just that understanding. You don't have to explain something that's going on all the time.

And we have a regular Christmas party and a regular picnic. They're attended by people throughout the province. You see these same people year after year after year, there's that connection as well. There's just a place to phone if you need to talk to somebody. If you've adopted or are looking to adopt a child with special needs you can phone the adoptive parent group and they have a list of parents who are willing to talk, so they'll give you a name and a number to phone. So they've got quite a support network. They also do a regular newsletter, that sort of thing. And they now have provincial funding. That's been real [pause] I mean most of the people I know, a lot of the people I associate with, it's been directly related to the adoptive parents group. And that's been really helpful.

As Eva noted, its members are doing an excellent job of providing emotional support and information. However, apart from an administrator and clerical assistant,<sup>6</sup> these people are volunteers who must deal with their own day-to-day struggles as adoptive parents. Both Debbie and Eva agreed that meetings are infrequent, since most members are too busy caring for their children to attend. Most contact is carried out through the newsletter and over the phone. When a member is in crisis, however, an adoptive parent will visit the home and help them through this difficult situation.

Similar praise was given by Paula and Josie for a support group run by SADAC, for parents dealing with teens who have addiction problems. It will be more appropriate to discuss the dynamics of this group in Chapter Seven, since this help came only when their sons were in their mid teens.

Researchers explain the importance of support groups for parents of children with disabilities:

Caregivers come to support groups for a variety of reasons: sharing experiences and coping strategies, information exchange, access to new resources, education, validation of painful decisions, understanding and companionship...Multiple-family education was significantly superior to single-family intervention in deterring relapse. This finding was attributed to the natural support network offered by the other families in the group format. In many ways the support group provides an empathic and functional assistance that the natural kinship networks cannot. Support group members understand the pain, know the system, are aware of the resources, and are educated about the condition. In many cases [when the group is allied with an organization]...support group membership is a prelude to advocacy. This is a role that enables caregivers to

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<sup>6</sup> These positions were also staffed by volunteers until provincial funding to hire two people was made available two years ago.



begin action-focused coping, to try to have an impact on the social policies and service systems that control their lives. (Lefley, 1997: 447-448)

Debbie and Eva leaned most heavily on the adoptive parents association. Susan, on the other hand, while she belongs to SAPA (the adoptive parents' association) finds it inconvenient to attend meetings since she lives outside the city. She has found them helpful, but gets most of her information and referrals to other agencies through the learning disabilities association. The aspect of the group meetings which she did not enjoy was that, from her perspective, people complained a lot, rather than getting on with their lives. The fetal alcohol group she refers to here is an offshoot of SAPA which was formed just this year.

Susan:

I decided that the fetal alcohol group was important, but not as important for our family. Whereas the learning disabilities association, there was more of an avenue of, through them, learning where you can go to get help. And what are more books that are available and so on. I think it's really nice to share experiences with other people but I found I was already getting that through SAPA because there were so many people there who were having problems with children which was all blamed on fetal alcohol. This is really easy to do with SAPA because it's not your child, right? I mean it's not your birth child, it's [still] your child. But it's very easy ...

We found in the adoptive parents group, when we were talking about fetal alcohol, a lot of the mums were very very resentful against the birth mums that they did this. And there's truth in that, you should be resentful. But when you've realised that and the child is there, there's nothing you can do. You can't change that, it's happened. My feeling is let's talk about what we can do to help these kids, not whose fault it was or something like that. I was concerned that belonging to the fetal alcohol group would be the same thing again! So for me the learning disabilities group was a really good asset and SAPA.

This supports the finding of Greenberg and colleagues (1997) that those with many friends who were caregivers of disabled relatives had increasing levels of pessimism and subjective burden. They suggest that when such mothers come together for support, they may tend to dwell on their difficulties.

It would be helpful here to specify other forms of support which parents found most useful. Spouses provided both practical help and emotional support. Family members and friends were generally supportive. Josie says that, "both our extended families were very interested in striving to understand Mark." As a single mother, Paula

relied a lot on the help of friends, especially when the boys were young. Her family had mixed reactions to the problems she faced raising her sons, especially when they began to get in trouble with the law.

Paula:

It's been hard. My family's found it hard because they, I think they are so angry about what's happened to me, you know. Everybody's a little different. I think my mum actually surprises me the most. She's tough you know, but she's actually quite soft-hearted with the kids. She's sometimes found it easier to give in and to say, 'Well you've got to give them a chance' than I have. Where my brothers, I have two younger brothers, they're pretty much, ...you know, 'They don't deserve any more... you've given them enough, cut them off!' And I think it's just the pain of it is all. But the one brother...had actually stepped in and taken them at different times especially Jason. Hired them to work in the summer and all that kind of stuff. He has physically probably been the most supportive. No, I've had a lot of help.

Paula belonged to several parenting groups over the years.

Paula:

And you see as time has gone on I have had support from family but it's been these parenting groups that just made it. One couple that lived just around the corner from me, who had two adopted kids who had major problems also, ... came to the parenting group because I recommended it. And we were in each other's kitchens every day. We went through a lot of that too. And our kids were friends so they had a connection with them, getting into mischief and worse together.

Well, there aren't many groups that I didn't try actually. There was a family service bureau and there was a church-run one that ran out of money quickly that I went to.

Susan is unique among these parents since she finds most comfort and support in her religious faith.

Susan:

And our church has been very supportive considering that in actual fact he is the only Native person in our church. And it's not been a problem. So I would say the support from the church and the community has been excellent, and the school at this point. For my own personal self [it's my faith]. If I'm going to write which has been most beneficial for James, it has

been the combination of working with [his counsellor] and that he's had an excellent school so far, that has been working with his needs.

Susan named her son's counsellor as a benefit to herself, her son, and the rest of the family. This counsellor provides help in times of crisis (for instance when her son ran away), is a sympathetic listener, and provides some respite for Susan while her son is in his care.

Susan:

So I will go to [the counsellor] and say we need to talk, and just give him the bare facts and I will say, 'Would you like to talk to James?' and then they will talk. We used to see [the counsellor] once a week, but now we see him every two weeks. Then we go in and for about twenty minutes to half an hour [the counsellor] and I talk, and he says, 'Tell me what's been happening over the past two weeks. Is there anything?' And sometimes we don't have anything to talk about and [the counsellor] and I have a cup of coffee. In the meantime James goes up to the toy room.

So if there's nothing, we'll just talk generalities, because [this counsellor] and I, well he's really a friend of the family and when our daughter went through a really really tough time when she was in her third year of college, it was [him] that we called on. Anyway, what I really like about the way the whole [counselling agency] is they're family based so not only are they treating the child, they're also treating the entire family and working with the whole family which I really like. Usually then for the next hour James and [the counsellor] work together. And they, I'm sure they do things through play therapy and you know stuff like that ... Sometimes they go for a walk. I don't always need to know where they are, he's safe. And so, and that works out. [This counsellor] has become, we're now to the point where we are friends, more so, the families too. We've been invited to their house and they've been invited to ours and so on back and forth. And we've gotten to know their children also. It's sort of exciting.

Susan's statements highlight the issue that it is "supportive" for her to know that her child is having his needs met. The peace of mind that this brings to her as a mother, is just as important to her as the more traditional forms of "social support" found in support groups and other direct services for parents. We also see how one individual, the counsellor, goes beyond his professional role to provide friendship to Susan and her family. As we will see in *Falling Apart*, Josie and Paula also depended on counselling to help them through some harrowing times. The different methods they tried with their sons had

mixed results. In fact here is a clear division between those parents who think counselling of any sort is “useless” with these children and those who feel it helps. This vital issue will be discussed in the next chapter, since mental illness is a problem faced by many teens and young adults with both FAS and FAE ( Famy, Streissguth and Unis, 1998).

Being informed of current issues is also an important component of support. Conferences are a vital source of relevant information which is presented by respected researchers and practitioners in the field of Fetal Alcohol Syndrome research. This situation would not have occurred even a decade ago. Michael Dorris, in *The Broken Cord* (1989: 227-234), gives a vivid description of feeling very much an outsider at an academic conference he attended in which researchers presented information in a very cold and detached manner and ignored the needs of parents:

It was unsettling to be the only parent of a fetal alcohol child, the spy in the midst of experts at play. At every session I attended, I had made an effort to introduce myself to presenters, as well as to scholars whose monographs and reports I had read. I led with my strong suit, my academic affiliation--Dartmouth was a respectable reference point. But as I continued to summarize my reasons for being interested--anthropology, Indians, a book, a son--I had the strong impression that I lost credibility with every successive identification...The lines of discussion seemed firmly defined by a preset index of topics officiously deemed worthwhile. Outsiders without known qualifications were not welcomed into the debate. When Eva Smith, the only American Indian physician in attendance, introduced material from her experience as head of the fetal alcohol program on the reservation where she practiced, no one responded or even asked for further explanation...At each subsequent annual meeting I tried to project a more palatable persona for myself. Anyone who has taught, especially at the university level, has had a brush with intellectual snobbery. The sanctum sanctorum of the elect, be they professional anthropologists, English professors, or creative writers, is by definition an exclusive club with easy scorn and a ready label for the amateur dilettante..[I was ] snubbed...because of being personally involved in the issue... (pp.228-229)

There are still barriers to such conferences for parents. Besides having to find the time and money needed to travel, they don't always find out about them because although they see researchers as an important part of the FAS/FAE community, researchers do not see parents as a part of the research community.

Debbie:

Eva and I hopped on a plane. I found out [about the conference] on the Internet. No one had told me of course.

[A psychologist] went. There was three of us from Saskatchewan, [the psychologist], Eva and I. And considering the incidence that we have here in Saskatchewan we thought that it was important enough to go to this conference. We just decided we didn't have a choice, we had to do it. We're really glad that we did.

She goes on to discuss the importance of seeking current, accurate information for herself and the support group members.

Debbie:

We don't get any information on how to do this from health, from education or Social Services. Nobody, you can't even get a book from anybody. So that's where we've gotten all of our connections [the adoptive parents' association and conferences]. I just can't emphasise enough. And when Eva and I went to, when I decided I was going to that conference in Seattle I phoned up Eva and I said,... 'Do you want to come?' And she phoned me back and said, ... 'I've just got to go too.' And we went, and [when we came back] we said all the things we knew to be true, that we weren't having validated locally [were true]. We said, 'We're not crazy, this is absolutely the way it is. We're not wrong. We just have a lot of work to do to try and pull this off.'

... I don't know what we would have done without that. And getting good information . ...I think support groups per se come and go; they meet particular needs and they go, but if you don't have support groups based on knowledge and information you can get yourself into some real pickles, and think that a certain strategy or whatever you're doing [with the child] is right when there's no really, it's not validated by anything. So I think it's real important to keep getting, increasing the knowledge of the group.

In fact, phenomenal changes have taken place in the ability of parents to access information even though barriers still exist. As discussed earlier, Fetal Alcohol Syndrome was not described in the medical literature until the early 1970s, and information did not reach a large audience until the late 1980s with the publication of *The Broken Cord* (1989). This book had a profound impact on all the parents in this study. It must be noted at the outset, however, that this information came a little too late for Josie and Paula who adopted their sons in the 1970s. Mark was never formally diagnosed, and Jason received a diagnosis as an adult in jail. Neither of these boys had their difficulties acknowledged, nor did they receive any form of suitable intervention. When these mothers sought understanding and assistance for their children, they found little knowledge or support from both the medical community and the education system. The

fate of their children, therefore, should not be seen as the future of the younger children in this study.

While Susan, Debbie and Eva must fight for every bit of information and every small accommodation or compromise they request for their children in their classrooms, they are fortunate to be facing this struggle at a point in history where research in this area is flourishing. Furthermore, access to the Internet is democratising research by giving people access to electronic medical journals, and even direct contact with medical researchers via electronic mail. This medium has been used to connect parents all over North America, and there is even an on-line support group. None of the parents in this study belong to this group, FASLINK,<sup>7</sup> but Debbie and Eva often glean information and articles from the Internet. Furthermore, they have attended conferences throughout North America for both adoptive parents and academics who research Fetal Alcohol Syndrome.

### **6.5.1 Spreading the Word**

A pioneer in the study of Fetal Alcohol Syndrome, who, according to Debbie and Eva, has always kept the needs of families in mind and has communicated effectively with both professionals and the general public, is Dr. Ann Streissguth. Both Eva and Debbie could not praise her enough. Debbie is impressed by the way a recent conference on FAS/FAE in Seattle was organised to democratise access to knowledge.

Debbie:

A lot of the people, I guess what was neat about that conference was that you know Ann Streissguth basically brought together parents, educators, social service people, justice, academics, like everybody together. And everybody was, no one was greater or lesser than the other ones. And there was people doing work out there, and there was real forum for collaboration.

She would be characterised as helpful “like a parent,” as Debbie explains.

Debbie:

And it's, when you find a professional that 'gets it', you recognise them immediately. Because they're part...because they get it. It's like when you sit down with another parent of FAS [children].

Eva paints a vivid portrait of this charismatic speaker at work. Dr. Streissguth evokes the feeling of a community united in a worthy cause; spreading the word about FAS/FAE.

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<sup>7</sup> See Morse, B. (1997) in References Cited.

Eva:

And a lot of the study has been done from Washington state. Ann Streissguth has probably singlehandedly done more for the cause than any other person and has promoted it. And her final words as we're leaving the conference is, 'Carry the Word.' You know, spread the word. And that's exactly what's happened. There were people from... countries around the world--Australia, United States-- and you take your knowledge back to those countries. That's how it starts!

She was fabulous, you know. She wore these brightly coloured outfits and she was just like this dynamo that would come charging into the auditorium. She'd come barrelling down there and she'd introduce every session. And she'd gotten her chairman for that session. She carefully picked these people to sort of pat them on the back and say, 'You're doing a good job, keep it up.' The guy from justice, First Nations was really well represented at the conference too. It was just really neat, and she was wonderful, you know. So many people got up and said [for instance], 'I'm a doctoral student from Wisconsin and I'm doing this because I was a student of Ann's five years ago, and Ann convinced me this should be my life's work 'cause there's no money in this as you know.' Person after person got up with this testimonial to her. So I think her and Sterling Clarren are really leading the pack. And he was great too. He basically got up and said, 'I can't tell you why, I scratch my head every day, why physicians won't diagnose this. I'm trying to find a way to make it easier for them to do that if they want to do it.' So he was great.

While all these forms of support are helpful, as Paula and Eva have stated, parents most value the advice and company of other parents in the same situation as themselves. Debbie describes how she felt when she first experienced this at a national conference for adoptive parents after attending several workshops on Fetal Alcohol Syndrome. She had finally found the community to which she belonged, which would provide her with avenues for support and information.

Debbie:

And it was wonderful to be in a room and sort of instantly bond with every other parent in the room. And everybody knew exactly what we were talking about without you having to explain anything. And that was so refreshing because I didn't know that that was [possible].

At a recent conference on Fetal Alcohol Syndrome last year, Eva and Debbie were

able to expand their network.

Debbie:

... But I guess the other thing is getting in touch with all those folks and [finding out] who's working on different things. The one thing that really, they posted a notice that said if there's any parents come by to the hotel [after the 'official' business of the conference was over], we've booked a room for twenty people or something. And then forty showed up and it just kept getting bigger and bigger and finally there was eighty or a hundred people there. And we ended up just sitting there 'till one in the morning going around the room going [for instance], 'Hi I'm Debbie and I've got two daughters.' And everybody said their bit.

The experience of other parents is valued highly. The parents in this study were willing to try strategies that other parents had recommended, because they have been tested "in the trenches." Information flows from parent to parent through books written by parents, newsletters, conferences, workshops, friends, and support group members. While this advice was not taken uncritically, mothers were much more likely to believe the experiences of other parents than they were to take the advice of a professional whom they did not know well or who could not assure them of positive outcomes of a particular intervention.

Eva displays enthusiasm for a new cognitive rehabilitation therapy they're trying with Tim.

Eva:

And what they're saying is if you have a brain injured child they can work with that child. I wouldn't say there's a cure but [what] they're saying is that they can fix it. [She admits] It sounds too good to be true. It does sound too good to be true, but it also makes perfect sense. So then Larry said, 'Well if it's so good how come everybody's not doing it?' It's because first of all, you have to find out about it; secondly, you have to believe it; and thirdly, you have to be willing to invest the time.

In order to conduct this intensive one-on-one therapy Eva is homeschooling Tim, and has taken several months off work. Furthermore, the hundreds of dollars in fees are not covered by their health plan. While this therapy is not accepted by the mainstream medical community,<sup>8</sup> strong testimonials from parents have convinced Eva that it is worth the effort.

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<sup>8</sup> Researchers are beginning to realise that cognitive rehabilitation therapy, which has been used with people with traumatic brain injuries, may be a valid treatment for individuals with FAS/FAE (Connor and Streissguth, 1996).



Mothers assume that other mothers, like themselves, are experts about their own children. There is implicit trust among parents.

Debbie:

[W]hen you sit down with another parent of FAS, there's no pretence, you know immediately what each of you is dealing with and what their needs are. No issues.

When parents can not meet physically, they may contact each other through the written word. Stories by other parents were named as the most useful source of information which mothers had come across.

Eva:

E: I don't know how much control you have over how you write your thesis but what's helpful for me is hearing the stories of other families and how people coped.

K: That's what you'll be able to read. People have talked about how they cope, and people cope in different ways, and the choices they have made.

E: And for people to make good choices they need to have really good information. And the more information out there the better.

E: When *Fantastic Antone Succeeds* came out it was the first book that I read that showed some positive [examples], that there was some hope there. So [in *The Broken Cord*] it was like you were getting a personal life sentence if you were given a diagnosis of FAS/FAE. I see that changing now. I think that once people take on the challenge like you're doing a thesis and this guy's doing his thesis, I think you're going to see some you know, that it isn't hopeless. We need to find out what works, rather than blaming. You know, it's not their fault. So what's going to work. But I think it was *The Broken Cord* that started all of this and it's just gone on. He got the exposure.

Susan also named both written stories and anecdotes shared by support group members.

Susan:

I think reading some of the stories by people who have been through working with fetal alcohol children you, when you read it in print from somebody else you think, 'Oh this is a lot worse than I'm going through.' Then you sort of count, you

start looking for your blessings instead of the bad things that are happening. I think I got the most out of reading other people's stories, how they coped with it. That was very helpful. And I think another thing that was really helpful was the parents, sitting down with adoptive parents' groups and saying, 'I tried this, it worked to this point. Does anyone have any ideas about how I can do things a bit differently so it would help my child? And so on down the line. Not just saying, 'Oh, this is too hard, I just can't do this anymore.' But the people who were genuinely wanting to help the child. Not just for the moment, but for the long term.... that was the most helpful.

It is significant that although Josie is an academic, with easy access to medical journals, she finds films and television programs the most informative and compelling.

Josie:

...[E]specially shows, some documentaries are excellent. There's one on Newsworld. It was about a family, and how they were dealing with FAE, and there are so many similarities. [I interject that this is 'David and FAS,' and she agrees after asking if that was the film in which they give the young man a video camera to record his daily life, thoughts and feelings. We agree that it was a powerful, moving film] That family is so much like us. You'll find, I don't know how many families you're going to have contact with, but many will tell you the same story as the family in the film. It was like looking at Mark, that could have been him. It describes Mark to a tee. So did a lot in Dorris's story.

In Chapter Eight I will argue that the telling of stories, either in person, through the Internet, or in print, film and video, has created a community; Frank (1995) calls it a "moral community," which is also a "community of interpretation."

## **6.6 Anticipating the Future**

In the stage of *living day-to-day* during times of crisis things may seem like they're "falling apart," but the family is able to cope with the help of their support system. As crises escalate in both severity and number, parents' thoughts are increasingly drawn to the uncertainty of the future. For instance, Josie spoke of her son's problems in grade five as foreshadowing trouble to come; it was a "peek into the future." By their children's early adolescence parents are finding it increasingly difficult to manage their children at home. Their greatest fear may be that the child will no longer be able to live with them. While parents express a desire for respite, they realise that the only option is usually foster care. Furthermore, they do not trust the social service system's ability to safely and adequately care for their children. They fear that they will be "lost to the

system” or will run away. Parents have made a commitment to raise this child to adulthood; if they had to give up now they would feel like failures. The term used by social workers to describe a terminated adoption, “adoption breakdown” (Triseliotis et al., 1997; McCreight, 1997) evokes a picture of dysfunction, failure and defeat.

John and Debbie feel like they are running out of services and running out of time. While Debbie believes that the medical and educational systems are going to have to change, because they are at their breaking point, change cannot come quickly enough.

Debbie:

Our problem in our family is can we hold out and support our kids until somebody comes to assist them besides ourselves, ‘cause we know we’re not going to be able to do this indefinitely. Well, we know that. We’re going to try this other program [the cognitive rehabilitation therapy]. It’s a private program, what a concept. Can we keep funding [pause] get money to do it? I don’t know. We’re going to try. Will it make a difference? I don’t know. We’ve got to try.

John was very specific about the program he wants his daughters to enter in high school. Since the entrance requirement is an IQ of 70, they are not currently eligible for this program. This means that their parents will have to negotiate with the school system to make an exception, or change the entrance requirements. He and Debbie will fight for their daughters’ needs in the high school, as they are doing now at the elementary school level.

John:

J: I know exactly where I’d like them to go. I want them to go into the LSWS program at [a specific high school].

K: And what’s the LSWS?

J: Life Skills Work Study. Unfortunately you have to have an IQ of 70 to get in. It’s different from the trainable mentally retarded program, the trainable mentally handicapped program they have up at [a different high school]. Basically, they assess the kids on an individual basis and they slot them into classes at the grade nine and ten level that they can handle. I [have taught ] them ...And they fit in very well...Some did grade nine science, some did grade nine math. They all did cooking and sewing, learning to do that. They had their own gym times together and they all have work projects. They handle all of the recycling [for the school], they handle all of the attendance pick ups, when they bring the notices, these are all [their] jobs.

As they get into their senior years, grade eleven and twelve, it's mostly they're learning about work and they're finding them jobs, protected environment jobs. And they're being supervised in these jobs by the teacher. And it's very protected. If after four years (they don't just graduate them) if they don't have a safe place to go they keep them for a fifth or a sixth year continuing to find them a job.<sup>9</sup> Up until the time that they have a safe living situation for them to go to and a safe working situation. ...And that's exactly what the girls need, but they don't qualify for the program, because their IQs are greater than seventy. Kate's is 83. So we're going to argue a few IQ points here, but that's the program or type of a program that these kids require. They need to have success so you put them into classes where they can succeed. If the kid can do math you put them in grade nine math, a modified section ... you have a group of them so they have peers. You don't force them to do things that they can't have success at. Even at lunch break one of the TAs [teaching assistants] goes down to the lunch room with them,... and they all sit in a group. And everyone looks after them at [this high school].

John indicates that the program's structure does not guarantee success, however. The entire school must accept these students as their own, and show them respect. This would rely on the leadership of the principal and teachers, who would need to work with the students to instil this attitude.

John:

We've got the same program [where I teach] and the kids are ostracised. They're 'the dummies.' But a lot of that comes from the kids that are barely making it, so they can pick on somebody that's in worse shape than they are. But that's where I'd like them to go and what I'd like them to do because that's the kind of a program they need. They need to be able to integrate where they can. Kate would just love to be in the shop, to work in the shop and do things in there, and she'd do well at it. She'd concentrate, she'd listen and she'd want to do well in that class.... She loves to read, maybe she could do grade nine English, again with some help, and grade nine science probably. But some of those other things like grade nine math, forget it. She'd never do grade nine math. So, she wouldn't have to do that... But that's what she needs, she needs a program where she can learn life skills, she can have success, and with the support.

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<sup>9</sup> Students can remain in high school school until the age of 21 if they can be accommodated in specialised programming (Marilyn McDonald, Saskatchewan Education, personal communication June 21, 1996).

He explains why programs like ‘Structured for Success’ do not work for Kate.

John:

There’s the Structured for Success program. But that doesn’t address their needs. The idea of the Structured for Success is you get kids into the program, you teach them how to deal with life, and then they take this back and apply it to their own situation and Kate can’t do that. She needs Structured for Success for life.

John and Debbie are not only anticipating their children’s future, they are planning for it.

Susan and Eva, whose children are younger, are still anticipating the future. They are investing in this future, however, by advocating for services for their children, and meeting their individual needs on a day-to-day basis. While they have made no firm arrangements, they were able to imagine and describe to me several “scenarios” for their sons’ adulthoods. Eva would like her sons to learn a trade (like their Dad). Susan mentioned that her father said he would be happy if James inherited the farm. Both mothers were comfortable with some level of “dependent living.”

They also, however gave me “worst case scenarios,” which were similar to those presented by Stade’s interviewees, “For the parents in this study, fear that their children would eventually commit a serious crime, be incarcerated, or be vulnerable to abuse by others was... significant” (Stade, 1995: 72). She gives the following example of a father’s trepidation about his son’s future, “Quite frankly it scares the hell out of me and X (his wife) to think that this child is potentially going to have to spend the better part of his life in and out of the prison system”(Ibid.). Stade points out the significance of the fact that the child in question was a two-year-old at the time of this interview! Another mother of a teenager states, “I mean I can see X killing someone in one of these rages. And five minutes later he won’t know why everyone is mad at him. And that will be it for the rest of his life” (Stade, 1995: 72). She continues, “Jails and penitentiaries are filled with people who have FAS/FAE. I hope he can keep his nose clean but I can’t predict” (Ibid.).

Two events in the past year have caused Eva to see an FAE diagnosis in a new light. First, she learned about the poor outcomes which were documented for individuals who have FAS or FAE but normal IQs (Streissguth et al., 1996) at a conference in Seattle where the findings were first released. Second, a few months later, she recognised some of the behaviours in her oldest son Cameron, such as poor social skills and shoplifting, which are possible signs of FAE. After taking him for an evaluation the diagnosis was confirmed. Eva is now very fearful for his future. Some of her statements imply that his future criminality is almost a foregone conclusion.

Eva:

You get a diagnosis of FAE, what does that mean? Well, it means you need to be aware that these things are very crucial, that kids will end up institutionalised and institutionalised means jail. And also mental health, a very high risk of mental health problems. [At the conference] one of the things she said is your child will do better if he has an IQ of 70 or less and they're diagnosed before the age of six, because then they're recognised as having a disability. The conference was on prevention of secondary disabilities, so the secondary disabilities like ending up in jail or the sexual abuse made me really aware and it's what prompted me to have Cameron assessed. Because I see him, he's out of that category. He wasn't assessed early, he's of average intelligence, I see him really lacking in the social skills and the social graces. So the sexual abuse, either as a victim or a perpetrator, I see him as a very high risk for that. So that is something I got out of the conference. That we need to look at trying to prevent them [developing these problems] rather than throwing them in jail. Are there are other things we can do. And also to be aware that there are secondary disabilities.

Debbie knew several families who had adopted children with Fetal Alcohol Syndrome who were in their teens at the time her daughters were diagnosed. She saw the difficulties they were having and viewed their experiences as her own potential future.

Debbie:

[at the national adoptive parents' conference] I went from fetal alcohol workshop to fetal alcohol workshop, because I knew that was it. I knew it was the problem with Kate. She classically fit the behaviour problems and the deficits that we saw and the timing for the difficulties was bang on. There were just so many clues; I knew. And what really scared us was we knew what Fetal Alcohol Syndrome was because we'd been part of the adoptive parents' group for years and years and we had friends with kids that were affected and we ...So that was when we really got frightened because we knew what the outcomes were, even then, three years ago.

These forebodings, lend credence to the hypothesis presented earlier, that association with parents in the same situation can perpetuate negative feelings.

## 6.7 Summary

This chapter has covered the process of *becoming advocates* which occurs during the stage of *living day-to-day*. In particular it focuses on the strategies of *navigating the*

*systems and creating the FAS/FAE community.* By creating a social network for themselves in the FAS/FAE community, parents are able to exchange information and be assured of unconditional support. This community provides a wealth of ideas for treatments and teaching strategies, gives them essential “inside” information which they need to negotiate the bureaucracies of the systems, and provides a buffer against the frustrations which they face as they do so.

## Chapter Seven: Falling Apart and Reconnecting

### 7.1 Introduction

This chapter discusses the stages of *falling apart* and *reconnecting*. First, the features of *falling apart* are outlined, followed by the stories of how things “fell apart” for Josie and Paula. Next, I will describe the salient issues which these stories reveal. Then, I will examine the interviews with Susan, Debbie and Eva to discern both similarities and differences among their experiences and compare these to the relevant issues raised in Josie and Paula’s stories. Finally, the features of reconnecting will be delineated, and the issues raised therein discussed. With great sadness, it must be noted here, as I explained in Chapter One, that Jason passed away in the summer of 1998, shortly after his release from the penitentiary. The following material must be read with this in mind.

### 7.2 Falling Apart

The phase of *falling apart* begins after parents have “tried everything” to manage their children’s problems within the context of the family and the school. Mothers spoke of reaching a breaking point, which occurred in the form of a specific dramatic incident which triggered the *falling apart* process. The term “falling apart” describes how the parents feel emotionally, the fragmentation of the family, and a deterioration in the child’s ability to cope with the demands of everyday life. This inability to cope is largely a function of the changing social context which surrounds the child, rather than being solely dependent on attributes of the individual child.

This period is characterised by frequent brushes with the law, which in some cases leads to incarceration, substance abuse, and life on the street. This is a dangerous time, when children are most vulnerable to harm or premature death. Parents themselves may be the victims of crime or verbal and physical abuse perpetrated by their own children and their associates. Parents continue to rely on their community supports, including counselling, in order to prevent a complete breakdown of the family, to maintain their mental health, and to make sense of their lives. If children survive this period intact, there is some hope that, as adults, they can establish a satisfying lifestyle, with some amount of support and supervision.

#### 7.2.1 Then Everything Just Fell Apart

While parents say that “things fell apart,” as we shall see later, what is related by the participants as a sudden fracture with a precipitating crisis, is actually the culmination



of a slow process of erosion of the family. Researchers report that when adoptions “break down” this is how parents, in retrospect, usually remember the experience (Bagley, Young and Scully, 1993; Krause Eheart and Bauman Power, 1995). Although Paula and Josie made active attempts to help their children (such as sending them to detox and AA meetings, and joining a support group to help them understand their children’s substance abuse) their narratives of this time evoke a sense of being out of control and of being overwhelmed by unfolding events. They are battered by a barrage of frightening, frustrating, and infuriating incidents which intrude ever more frequently on their everyday lives. Paula and Josie both used the phrase, “just one thing after another” to describe this stressful stream of events. I contend that this time was especially disturbing for these mothers because they lacked a coherent frame of reference in which to place their sons’ actions. They were unable to understand them, to make them meaningful. While Paula and Josie had some knowledge of FAS by the time their sons were teenagers, this information was incomplete: they held only a few pieces of the puzzle. Both mothers described this time as the most difficult stage of raising their children.

Paula began to experience serious difficulties with Jason when he was just beginning high school. At this time Brad was still in elementary school and doing well in his modified program. Paula did not report that Brad caused any problems at home until his mid teens, but that he did require quite a bit of supervision.

### **7.2.2 Jason: A Bleak Story**

Paula states that the “real trouble” didn’t start until Jason was in grade ten; however, he exhibited aggressive and cruel behaviour from an early age. We have established in earlier chapters that he showed little emotion as a young child. He was also very rough with his younger brother, Brad.

Paula:

He was always pretty jealous of Brad. I think because Brad was kind of a sickly allergic kid and needed a lot of attention. I think it was really hard for Jason when Brad came along . He was a bit rough with Brad. I know I tended to sort of minimise it but Brad’s foster grandma was very unhappy with it, with the way Jason treated Brad.

As the boys got older the abuse increased.

Paula:

...[B]y the time Jason was twelve and thirteen he really was quite abusive to Brad, he was very controlling and we started going for counselling at youth services. More, I mean I began on Brad’s behalf to see what we could do about the fact that Brad was very dependent on Jason and it seemed like he kind

of led into these instances of wrestling that would get really out of hand. What happened a few times when I left the two of them (by this time Jason was twelve or thirteen and could stay alone) but there were some really quite abusive things that he did. So Brad and I went [for counselling] and Jason went a couple of times and then refused. You know and it was helpful, but nothing ever changed.

This escalation in physical and verbal abuse towards his younger brother coincided with difficulties which Jason was experiencing at school. His mother explains that as a young child Jason was eager to please adults and was a high achiever at school. Once he put his mind to something he would work very hard to achieve it. He often had the highest marks in his class.

By grade six, however, Jason was finding mathematics extremely difficult to master. At this time he also began to become somewhat rebellious at school.

Paula:

He just, he got to a point where he just wasn't comprehending math at all. And some of it was discipline but some of it I think just that he was having a lot of difficulty. And he'd try but he just couldn't do it... and there were some thefts. Some kind of suspicious stuff with other kids, abusive stuff bullying kind of stuff on the playground.

Although rebelling against authority is a normal stage of development for children, Jason became increasingly marginalised; he began stealing and built up a group of friends who engaged in criminal activities. This is consistent with Paula's description of her older son "giving up" if he found he was unable to understand or complete a task. He was only interested in pursuits in which he excelled.

School, however, was not a completely negative experience in Jason's early adolescence. Paula relates that teachers that were encouraging and accepted Jason for who he was made a world of difference.

Paula:

And he did quite well [in grade six], he had a teacher that really took an interest in him. He's got very great skills in English actually and he's always done well in that. And meanwhile he got into band, and he just loved band and trumpet. And he had a trumpet teacher that he just adored. So there were these sort of things that were quite positive going on.

I sort of think about Jason in grade nine or so or ten, the teachers that really did get his cooperation and that he coped well with even at that point were the ones that somehow were

able to encourage him and make him feel good in their class. So there are ways to do it, you know. And I presume that it was a two way thing, that the teachers that didn't get his cooperation also had some responsibility for that. I don't blame them really because I was in the same boat as they were but still, if people who deal with kids could learn how to get the best from them then that would be good.

He had one or two teachers, he adored the art teacher at [his first high school]. She was crazy I think, you know she was really off the wall and all the kids liked her. And an English teacher who really engaged him. And he was still at the point where people, if he liked them and wanted to, he could really do well. But math and science were hopeless.

Unlike his brother Brad, and most children with FAS/FAE who are easily influenced by others (Streissguth et al., 1985), Jason was always a leader.

Paula:

And he was really into a sort of gang mentality I think. He was organising the kids in his class in different things by the time he was twelve or thirteen.

Even though Paula was often called to the school because of her son's thefts, fighting, and disobedience she saw this as normal, or at least tolerable since she felt things were still under her control.

Paula:

[There were minor things] but you know, I think nothing that seemed really out of control until the end of grade eight. He didn't want to go on to grade nine. He was having trouble and frustrated and causing a lot of trouble. And we sat down with his favourite teacher ...and [Jason] said he just didn't want to go to high school. Why did he have to go? But you know he was passing and they were suggesting some remedial help but otherwise he was doing alright.

The inability to perform academically must have been humiliating for Jason who was such a perfectionist. Gradually, the negative aspects of school came to outweigh the positive ones. His high school career was both rocky and brief.

Paula:

So he did go on and he chose a fairly academic high school. I think for the first six months or so he just kind of sat in the back row and didn't say anything. He didn't cause any trouble. And then he started skipping and... breaking into

lockers. You know hockey cards were a big thing, and he was in on a sort of theft of cards and hats and t-shirts from kids' lockers. Just one incident after another by the end of grade nine.

In the summer between grade nine and ten Jason worked as a counsellor at a church run summer camp. While there, he met an old school friend who was now heavily into Satanic worship. Jason got involved with Satanism himself, and terrorised his younger brother with this new interest.

Paula:

He was talking to his younger brother especially and Brad would come to me and say, 'Oh Jason says this, Jason says that', you know. And...there was a whole lot of power stuff, you know like control or manipulating.

The situation at both school and home deteriorated through grade ten to the point where Jason was living on the street.

Paula:

I noticed a really big change through grade nine and grade ten. He changed schools, he went to a less academic school, it was in the neighbourhood. And then through grade ten, things really fell apart. He was arrested for shoplifting and I noticed drug stuff around the house and confronted him and the school was confronting him. Some of his friends were being arrested and, you know, there were just different incidents one after the other. As a matter of fact I think he was in [juvenile hall] before the end of that year.

Paula was able to recall vividly a specific incident which led her son to being formally charged. This was his first contact with the justice system.

Paula:

The first kind of trouble with the police he was at the end of grade nine. And he actually took my mother's car. It was the kind of thing that isn't so terrible. You know, joy riding around the block and couldn't get the car back into the garage and smashed it, or smashed the garage. And he was with another friend and the neighbours called the police. And Mum charged him, we went through the whole process and he was charged. And that was the first that he'd been in any kind of trouble. He would have been nearly fifteen.

Although this charge only led to mediation, Jason was soon increasingly involved in

criminal activity, and life was becoming increasingly stressful for his mother and she had sought counselling for Brad and herself. She was called to court over and over again, becoming not only frustrated, but demoralised by what she saw as a futile exercise. Finally she gave her older son an ultimatum.

Paula:

And I used to feel really cynical when... I used to go to court a lot with Jason and finally I just said, 'That's it, I'm not going to go with you again. This is not the way I want to spend my time. I'll lose my job if I take any more time. You stay out of court or you're on your own.'

Her counsellor suggested that she seek a residential placement for Jason.

Paula:

But then the next year everything just really, he really was in trouble all the time. He was picked up for shoplifting. There were maybe three or four different charges, and then finally he was actually kept at [Juvenile Hall]. In the meantime around January that year,...things were getting really bad at home and [our counsellor] said, 'Look, you are going to have to have him in residential care, you can't cope with him at home. It's just a matter of waiting until you are ready to do it'

She resisted, however, since she felt that making Jason leave home was abandoning him, and abandoning her duties as an adoptive mother.

Paula:

Eventually, and this was what [the counsellor] was saying, 'I'm just waiting for you to be ready, to realise that you can't cope with him at home. I can't make you put him into a group home.' And I was really struggling because of adoption and you're really fighting this adoption breakdown, you know. Somehow that's always there as a spectre. And so I think I was just sort of feeling well if I once say he can't live in this home that'll be it. And in a sense it really did precipitate a crisis for him. But on the other hand I think I was overcautious. If I had it to do over I would certainly have him in a group home much earlier, when he didn't have quite so many skills for getting away. Friends with cars that just came and picked him up and that was it. But at fourteen [for instance], you can get help to him a little more easily...really felt like I was saying this is the end as far as having adopted him. That was what I was fighting in myself.

Short-term stays in group-homes or other residential facilities should not be termed a

“disruption” or “breakdown,” but should be thought of as respite (McCreight, 1997; Bagley, Young and Scully, 1993). For older adopted children who have been abused and neglected, the adoption

should be seen as part of a continuing care progress, with adoptive parents working co-operatively with other members of the youth care team. Occasional spells of the adolescent in residential treatment care should not be viewed as a failure of adoption, but as part of the continuation process of care, therapy and healing. (Bagley, Young and Scully, 1993: 62)

Furthermore, Mark, Brad and Jason had been with their parents for over ten years before they were forced to leave, which is very successful in terms of children who have been abused (as had Mark) or were older at adoption (Mark and Jason):

[as] more older children with special needs are placed for adoption, so the number of adoption breakdowns or “disruptions” (temporary breakdowns) increases: about 10 percent of such adoptions will disrupt within a year of placement. Half had disrupted within five years. (Ibid.)

Paula finally reached her breaking point. She remembered this agonising moment with clarity.

Paula:

And finally I was ready. I just sort of stayed up all night by myself, tearing my hair out, realising I was just making things worse. Stolen things were starting to appear in the house and rough, rough kids coming and going. And so I took him [to an assessment home]. And it was funny, he became like a really small child. Like it was a really traumatic thing for him when I finally said, ‘You can’t live here and behave like that. We can’t cope with you here; we’ll have to try somewhere else.’ Anyway he stayed there for about four days, running everyday and coming back at night. And finally just took off. That was it. He really wasn’t at home again after that, he was on the street. He broke into a couple of homes and took a bunch of stuff, and lived under the bridge with a bunch of friends, doing break and enters. [While living under the bridge]... an older fellow had them kind of doing petty thieving and stuff and they were picked up stealing cigarettes from a drug store and... also stole guns from a gun shop.

Although he did not contact his mother, Jason stayed close to home committing break and enters on houses in her neighbourhood. His mother says that the situation was tragic in a way because he was hurting the very people who had tried to help him. It was also humiliating for her.

Paula:

And, oh he stole my mum's credit card. There was just a whole rash of things. That first summer when he was on the run, he broke into a friend's house, a friend of ours. [He] lived in the house with a bunch of kids, wrecked his car, drank all his liquor and ate up all the meat in the fridge. You know it was just one thing after another. [His] friends' houses were broken into. Everyone that knew him suffered [laughs] for having known him, you know.

Jason returned to school for a short time, but was soon arrested for stealing and pawning stolen goods. Between the ages of fifteen and sixteen Jason had spent only a two week period at home. His mother said he could move back on the condition that he remained drug free, and Paula asked him to leave when he tested positive for drugs. Next, Jason was arrested several times, each time being placed in increasingly restrictive youth detention facilities, each time running away.

Paula:

I can't quite remember the whole sequence but he was in custody again within about a month and then [pause] Then he began making these escapes, they put him in [Juvenile Hall] and he escaped about three different times from there. And then he was in [another city] for a while in a youth centre there.

Even when her son was in custody, however, Paula was still under a great deal of stress.

Paula:

We're sort of anxious, like we've had break-ins. Every time he escaped our house would be broken into and everything that we had [was taken], because that was the way he was getting money.

Despite all the heartaches he had caused, Paula did not want to give up custody of her son. He wanted to move in with a friend at the age of sixteen, and she refused to sign a form which would have put him into the custody of Social Services so he could get welfare. She said that she was still willing to provide a home for him if he wanted it.

Paula:

Yeah, there's some sort of section nine or something, where in order to get support at age sixteen they can sign themselves into Social Services care. And I went down and I would not sign whatever it was because at that time I felt he could have lived at home. I was prepared to support him. You know,

there were rules at home that he wasn't willing to follow. But he just didn't come home anyway. He lived with a bunch of kids [on the street].

As time went on, Jason's crimes became increasingly violent.

Paula:

And he was involved, I don't know if you remember ... there was kind of a big deal in the paper about robberies with violence, like they were bringing weapons around. That was when he was picked up ... in relation to some break-ins and that's what these recent charges are. But with axes you know, the sort of thing where there was clearly the intent to violence even though there wasn't any actual violence.

And finally, the final thing was he was given actually an eighteen month sentence probably about the time he served... he was nearly seventeen...[T]hey were living on the streets and he and another friend took a fellow and extorted money from him by locking in the trunk of a car. Really really violent, really nasty violent stuff. And he then was given this eighteen month sentence in [the penitentiary].

Ironically, Paula says that things settled down for Jason once he was in jail. He was able to complete some high school courses and even took a university class in Native Studies. However, Paula regrets that the only place which was able to offer her son some sort of stability was prison, because he has become institutionalised, and has taken on the identity of of a hardened criminal.

Paula:

I think he thinks of himself as a criminal, I'm sure he does. That's his image of himself. Big time gangster kind of, that's his view of who he is. Just next time he's not going to get caught. I'm sure that's his only real regret.

### **7.2.3 Brad: He Was Always at Risk**

Up until the age of sixteen Brad was doing well in his modified program at school. But his mother was worried about the powerful hold Jason held over him, and feared that her younger son would be lured into a life of substance abuse and crime.

In high school, Brad was a member of the football team, and enjoyed many other social activities. His welding teacher was very encouraging, and had arranged a work experience for him at a local company. As long as he was not taking drugs he coped fairly well. His mother says that he learns and functions much better in a group where he is accepted.



Paula:

...if he's in a group where he feels comfortable he does much much better. [He successfully completed a regular drama class with the support of his teacher and the other students. However], ...he didn't quite finish his grade ten. He actually plugged away quite normally at this modified level 'till the last term of grade ten when he turned sixteen. And then he just, it all just fell apart .

She recounts a particularly troubling incident which happened when Brad was still in school.

Paula:

The last time [Jason] was picked up he had a stolen car. He drove along and saw Brad walking home from school. He offered him a chance to drive this car. Brad knew darn well it was stolen, I mean it wasn't innocent on Brad's part. Brad couldn't drive a standard very well and they drove so erratically that the police stopped them and picked them up...[T]hey had stolen property in the car, and Jason wanted Brad to say it was his responsibility, that it was his car... [T]hey took Brad into the patrol car. Once he was away from [Jason and his friends] Brad gave [Jason's] true name[he had used an alias] which Brad said they checked on their computer. And then called for assistance and arrested Jason 'cause he was on the run at this point. But Brad had the nerve to tell on him once he wasn't in his presence. But I think as long as Jason is right there with him...Brad was terrified because he was supposed to have to testify against him in court...But in the end it didn't come to that, so he didn't have to.

His mother explains how his struggle with substance abuse started.

Paula:

Brad sort of held everything together fairly well until about age sixteen ... I don't know when it actually started...I wasn't that aware of it until he was fifteen and a half to sixteen. And he left over the time of his birthday... he left for about a week just on a total binge and then he came back. But I knew through friends where he was, that he was at this party. Then he phoned and wanted to come back so I said okay but the way back is to go to detox, so he did...And then he hasn't been so involved with legal stuff [as Jason] but he has been drinking and drugging. And he has a natural family that he has been involved with all along. And by this time the older two [natural brothers] were on the street and he went to live with them then. Then Jason got involved with that bunch as

well...and so he was influencing Brad and having Brad in this sort of gang of kids.

For the next year he lived on the street, moving in with his biological mother when winter came.

Paula:

And when Brad left me he went sort of running around on the street and then [his birth mother] called me and said, 'He's showed up here and he needs a place to stay. Do you mind if I take him in?' And I was glad that she did. And he lived there for a while. Then just started stealing from them and getting into trouble there and she kicked hm out. [I]n a way it's been good for me because I can sit back a bit and see exactly the same problems [happening with Brad] in another household, a much freer household. I don't think she had any rules at all, almost none. And what was happening was that he was kind of abusive. If he'd come home drunk then he would be actually somewhat abusive.

By the following summer, however, Brad was tired of life on the street and decided to voluntarily go into detox. This led to a reunion with his mother, and a period of more stability in his life. Brad has had the same girlfriend for a couple of years, and they have an infant son. Here Paula comments on Brad's paradoxical nature, and his relationship with Jason.

Paula:

But you know there's this really strong fear. Brad's three and a half years younger [than Jason]. So he's just eighteen and a lot younger as far as his social sophistication. Brad's in my mind doing better and better. Longer time between the sort of binge bouts and being quite responsible at times with this baby, much more than a lot of people's eighteen-year-old sons would be, he really is. He's living in some ways like a twenty-five-year-old, and yet at other times he's much like a twelve or fourteen-year-old.

#### **7.2.4 Mark: School for him was Demoralising**

Mark had a rather unusual childhood, travelling around the world with his parents and older brother. Each country had a different school system with different expectations. While his mother's difficulties during his early childhood were discussed in *adjusting*, his starting school only caused more frustration for his parents.

Josie:

And then I would say that our strategizing increased as Mark

got into school. Because then we had another set of problems to deal with, the expectations of the school which he didn't always meet. And then, so how to make sure that he would do the homework that he needed to do. Talk talk talk talk, constantly [laughs].

He was first homeschooled by his parents while they were in Peru, and entered kindergarten at the age of six when they moved to the United States. He managed to keep up quite well in grade one, but began to have some difficulties in grade two when he entered a school with a very demanding curriculum. His parents worked hard to help him keep up with his classmates.

Josie:

Well, [the schools in this African country are] like European schools, the French, Spanish, very much accelerated. In grade one they teach you all the basic math, multiplication and division as well as addition and subtraction. Mark didn't have a chance in this environment academically. We kept him there so he could socialise and learn the language. The teachers there described him as playful, not able to settle down, flighty. We homeschooled him twice a day. Math in the morning and grammar and writing in the afternoon. He made good progress this way when we worked with him one-on-one, and for briefer periods of time so he was able to concentrate.

Even though there was close cooperation between his parents and the school, it became more difficult for Mark to perform at the expected level as the years went by, and the classroom material became more demanding.

Josie:

For grade four and five we had moved back to the States for two years. This was a time when we spent a lot of time at the school, talking to his teachers. We would get notes sent home about how he'd been in class and what work he had to do that evening. There was a homework book that was sent home that we had to sign...A lot of friction developed over the monitoring, we had to keep at him all the time. It was very hard, that was a difficult role to play. This was frustrating. It was frustrating for us and for Mark's teachers. It was then that we first saw some of the more troubling behaviours developing. We had a peek into the future. He was well liked by his teachers. Teachers always liked him. But he was frustrating to teach. They just couldn't handle him, didn't know what to do with him. We seemed to be able to accommodate him better at home. For grade six and seven [he went to] a public school in the neighbourhood. This is when

we first tried Ritalin and [the psychiatrist] diagnosed him as ADD.

Josie discussed some of the behaviours in Mark which she attributed to his ADD, and how this affected his performance in school, and his choice of activities.

Josie:

He had a short attention span which required a lot of monitoring and trying to provide less intrusive surroundings at school. The attention deficit was clear, but if Mark really liked an activity, he could focus on it for hours. For instance, his thing was Lego. He didn't watch T.V., I think it was too much stimulation for a hyperactive child.

His emotions were unusually quick and dramatic, he could be very angry one minute, then smiling sweetly the next and forget what he was angry about. He had an irregular learning ability, ease in some areas, and almost unteachable in others. For instance he could understand algebra but not seven plus two. But not for any length of time; knowledge was fleeting.

Math was always hardest. Math was Greek to him most of the time. The same with science. Anything abstract. He did quite well with reading and writing.... The way the teacher described [his attention problems] he just wasn't following things, he wasn't tuned in. But if it was something he was really interested in, something he could understand then he didn't have the problem...Mark just wasn't with them. He would get lost or find things too difficult and just drop out.

The erratic emotions, poor memory, and difficulty with mathematics are a problem for many individuals with FAS/FAE (Streissguth et al., 1991), and particularly for Kate, Jason, and James in this study. Furthermore, while recent research suggests that the types of attentional disorders in FAS/FAE and ADD are qualitatively different (Coles et al., 1997), many children with FAS/FAE exhibit hyperactivity, and may even have a dual diagnosis of ADD and FAS/FAE (Ibid). Also, getting frustrated easily and giving up or appearing to "tune out" because they shut down when faced with sensory overload is a common problem (Raymond, 1997). Josie realises that Mark's needs were probably not being met in a regular classroom.

Josie:

Well, I suppose sometimes [the teacher noticed that he wasn't following the lesson]. But I don't think teachers can always, they aren't equipped when they have to deal with an entire class to pay attention to each individual child like that.

As Mark got older, his difficulties in school only increased, but his parents continued to do everything they could to help him succeed.

K: What kinds of things did you do at home to help Mark learn more effectively?

J: Me, one-on-one and monitoring daily homework. I primarily took the enforcement role and sometimes Mark would resist, didn't want to do the work, or do very sloppy work.

K: What effect did this have?

J: It helped to a certain extent and for a certain length of time. It got more difficult as he got older, he became increasingly resistant. He'd do things like not coming home on time. It was less easy than when he was younger and we had more control.

By the time Mark had almost reached his teens, he was starting to get into trouble at home, and even had some brushes with the law. This was especially true when his father was away, as was discussed in Chapter Four. His mother was often overwhelmed at these times.

Josie:

... Mark would have been twelve. Starting then the amount that they tried to get away with increased. Twice Mark was involved with the police in [that city], when he was twelve and thirteen. One time for shoplifting and one for stealing bicycles with Ian and another kid. But even just at the home front, from then on they tried to get away with a lot more. But they were old enough by then that if things got too bad and I was on my own I just walked out of the house and went to a movie. Just to save my soul [laughs]. Couldn't do that when they were smaller. But it was a little bit easier when they were smaller. They weren't quite so intrusive.

When he was still not making any progress in school by grade eight, his parents sent him to a private school where they thought their son would have more individual attention.

Josie:

We were living in [the city] when he was in grade eight and he went to a neighbourhood public school. A lot of work went back and forth between home and school. But the teacher didn't really know what to do with Mark and became increasingly frustrated. After that we decided to send both boys to a private boys school in Alberta. We thought Mark

might have more success there with the more structured environment and smaller classrooms. Also we wanted to get them away from the racism they were facing in [the city]. Ian thrived, but Mark just hated it. He was very unhappy and wanted to leave. We told him if he could finish the grade nine course work he could leave. But he didn't, didn't finish it and we didn't make him go back.

Mark did not complete much high school. Like Brad, he enjoyed the social aspects but found the academics frustrating. Josie says that he enjoyed the arts, but mathematics and many other subjects were completely beyond him. Eventually, he dropped out of school.

Josie:

At this point I really start to lose track of things. Mark played 'musical schools.' He started in [one high school] and was getting some special ed., but the school couldn't deal with him academically. Oh yes, we also took him to a private tutor at this time...a private education consultant. We worked with the school a lot, but Mark dropped out. He started becoming truant and eventually he dropped out. He went to [one high school] for a while and [then another]. As academic expectations got higher he got more and more frustrated. With the truancy it just became a game of deception, trying to get out of doing things. He started drinking around this time and a whole new set of problems started.

Josie says that Mark's experience at school was so negative that it led to a cycle of heavy drinking and depression.

Josie:

School for him was not satisfying, was not enjoyable, it ...didn't contribute to his self esteem. It was a demoralising experience, the classroom material itself. He was enough of a social character to enjoy the social aspects...[His drinking] coincided with his [lack of an] ability to stay in school. It was, once he got into [pause] he could not handle high school subjects. He did some grade nine classes and he did a small number of grade ten classes. But it got well beyond him. And he's a smart kid so its not just frank intelligence, all the other stuff... I think he moved, I would say that later, maybe in the last three years or so he would have depressed spells, and suicidal, you know, thoughts and things.

His bouts of drinking made it impossible for him to stay in school. Josie remembers clearly when his real trouble with alcohol began.

Josie:

Well, I can remember quite clearly when he started, when we knew he was drinking. I think he was, now let me get this right, sixteen and three-quarters. It was May. He went out one evening with a friend, who we did not know at that point, and he didn't come home. And uh, so tracing through friends we finally located him late the next day. The parents of this boy were away so they had partied at his house all night. So that was the first we knew that Mark had a problem. So that was May, by September if I can remember correctly, he was getting just more and more unresponsive. He would not follow rules anymore. So we took him to [the psychiatrist] again, and [he] put him into [the training residence]. And he stayed in there for a few weeks, met another fellow there, and then just [pause] he was discharged and just about the same time he and this other boy were arrested. So it was the first experience with the law. Well, not the first, but the first big one.

She continues the story.

Josie:

So, about one in the morning the police came to our door and asked did we have a son, Mark. We said yes. He and this boy he had met at [the training residence] had broken into my sister's house to steal alcohol. We came home later and I said I couldn't handle this bullshit. I was trapped at home to deal with these things. I went to a relative of a friend of mine who works in counselling, and she has also adopted a Metis boy who has a drinking problem. And I had already started to label this as a type of alcoholism. So I went to SADAC and started [attending] a parents' group there. And then we just, things were so out of control, that we gave Mark our ultimatum. Go to [the treatment centre] or he couldn't stay at home any more. So he went to [the treatment centre]. But got kicked out just prior to family week. And we were all bright-eyed. We'd booked time off work and got Ian out of school. And just days before we heard from [the treatment centre] that he'd been kicked out. I think he got himself kicked out. I don't think he wanted to face all that was involved with family week. Because its a really "come clean" time with the family. It's a very difficult but cathartic experience. I think he thought it would be, well [laughs].

Oh, I remember something else that happened in the fall before he went to [the treatment centre]. The last straw was Bob was away, I was down east at a conference, my mother who was about eighty at the time was staying with the boys. Mark went and got Bob's credit card, went down to [a hotel], booked in

on the credit card, invited all his friends. They had a huge party and the hotel did nothing. There were all these people coming and going. They were drinking all night long. And then they wouldn't accept his signature. There was a bar bill of about six hundred dollars. So Mom called me. The hotel called Mom and she called me in Toronto. [Laughs] What a nightmare for my mother. So it just went on from there, one incident after another.

This incident occurred when both of Mark's parents were away, and he was in the care of his grandmother. Josie reported that similar, but less serious, incidents occurred when the boys were younger and they were left with friends or family when their parents travelled.

Josie and Bob did not abandon their son, but ensured that he had access to counselling, alcohol treatment and support from Alcoholics Anonymous. Mark spent a stormy couple of years in and out of several institutions.

Josie:

[A training residence that] we found out about from Youth Services ... He was in trouble with the law, broke into my sister's house. [The psychiatrist] put him in there for a few weeks. They get counselling and nursing services. [The treatment centre] for about nine weeks [about a year later] for detox., [another] treatment centre, [a] Correctional Centre, [Juvenile Hall], [youth detention centre].

His life finally started to settle down when he decided that he wanted to get in contact with his birth family. Josie explained that Mark became interested in his Native roots when he was in his late teens. She was reluctant at first, but realised that she could not stop her son from searching for his family, and was also acutely aware that he could no longer live peacefully in her home.

### **7.3 Parents' Support Group**

Both Paula and Josie credited the support they received from the SADAC<sup>1</sup> group as the only thing that saved them, that held them together during the most stressful period of raising their sons. The group was formed to provide support for parents of teens who have drug and alcohol problems.

Josie:

We got involved with SADAC when Mark was into booze, to try and understand his addictions. This was about... for three years... I'd say the most practical help was through SADAC,

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<sup>1</sup> The Saskatchewan Alcohol and Drug Abuse Commission, who sponsored the group.



we got lots of help through them, but not for FAE specifically.

and

Paula:

And I think the SADAC group (for a while I went to two groups at the same time) and the SADAC group was a little different. It was much more how to cope with drug and alcohol [problems] ... this whole codependency thing. They really focused in on how to look after yourself. The other one was more of a whole family thing so they really complemented each other.

Josie explains how the group worked.

Josie:

The SADAC program was the only thing that held us together. We stuck with that for about three years. It was immeasurably helpful. It was nothing to do with FAS [but for] kids with problems with addictions. Well it's just an excellent resource. Now SADAC there is no longer... They were always part of Sask Health but they are now Addictions Services or something. They're renamed, I don't know how they're reconfigured. I don't know what their programs look like. But it was... the first phase that a parent would go through is an information series of about eight weeks, weekly [where you get] a lot of information about what this was all about. Then if you chose to you could go into a parents' support group that met weekly, and it was facilitated by one of the counsellors. So, you got both the mutual aid and the self help from the other parents plus the guidance of the counsellor. It was the only thing that saved us.<sup>2</sup>

Again we see the focus on both support and information which the parents felt were necessary for a successful support group.

Paula offered a specific example of some information which she learned in the group and was able to apply to her own situation.

Paula:

Yeah,... I think one of the breakthroughs for me really, I don't think [the SADAC counsellor] would like to hear it [because she tended to minimise the importance of FAE] but it really was when she started talking about fetal alcohol effect. And

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<sup>2</sup> It is interesting to note that this description came immediately after Josie related a very emotional experience, and may have been a way of diverting the conversation to a less painful topic.

talked about this as almost something that's common to many families and somehow related to something that I couldn't have changed anyway. Because a lot of time you're thinking I've got to have control here, I've got to have control here, I've got to find some way that I can change this so that it's back, so that it's tolerable, it's back under my control.

Her next comment shows how parents, beyond a certain point, must learn to let go.

Paula:

But most of the things that were helpful for me to cope, didn't change what went on for Jason. You know, I think that was almost a motto for us in the parenting group was: we may not be able to change our kids but at least we can find ways to survive...and maybe find ways to keep our own family intact through it, accepting that our kids may leave, or end up in jail or whatever happens. And some really horrible things happened to kids through that time with those families.

But at least, our purpose wasn't to change the kids at all ...or to work on their behaviour at all really. It was how are we going to cope, how are we going to make the house sane. Two or three situations where there were couples going was how are we going to keep our marriage from falling apart trying to cope with what's going on with this kid who's trying to manipulate both of us against each other.

#### **7.4 How Things Fell Apart**

Both Josie and Paula realised that the school system failed their sons, and probably contributed to their marginalisation. Furthermore, Josie stated that early trauma and neglect in Mark's birth and foster homes had left its indelible mark on him.

Josie:

He certainly had his own horrors and those would come out during the night. I think most of that was based on the emotional and physical trauma that haunted him always.

Paula thought her sons probably had a genetic predisposition to alcoholism, given the alcoholism in both their birth families. Josie felt that Mark's FAE was responsible for his rapid descent into alcoholism.

Josie:

Oh, I think the reason from the time he first tasted alcohol and became an alcoholic almost from day one was because of the

F.A.E. And I don't know the literature on that, if it would substantiate this, but he was never [pause] there was never any development for him, it was very [pause], it was either he didn't drink or he had a problem. And all the judgment stuff, I mean breaking into my sister's house. He was never smart enough, never devious enough [to break the law]. He learned to be after a while. I'd attribute it to the F.A.E. because he's not a bad kid.

Both Josie and Paula believed that the F.A.E. explained Mark's and Brad's poor judgment. Paula maintained that Jason had more control over his behaviour, but conceded that he often repeated acts that caused him pain and trouble, from which he learned nothing. She went as far as saying that she would list this inability to learn from mistakes as a "red flag" or distinguishing feature of F.A.E. Jason had an aggressive personality which led him to committing increasingly violent acts. His mother came to fear him.

Paula:

I've got to the point where I was physically very afraid of Jason...There was a lot of real just unlimited sort of anger.

Jason also had a very negative influence on his younger brother, abusing him both mentally and physically. Brad was also drawn into criminal activity by both Jason and his biological brothers.

Josie had some very specific criticism about the school system, especially one of the high schools her son attended.

Josie:

...[W]ell, what would happen is we would sit down and plan with the teacher, we would strategise. But the schools weren't really equipped. What was lacking was an organised program, like a consistent resource person to keep track of his progress and so on. So no, there was never any real plan....We could make suggestions, but there was no formal process or plan, we didn't have a specific role as such.... [What we would suggest was] based on our experiences, and with what had worked with other teachers, other schools...to try to keep some continuity. [We had good communication with the schools] and Mark had some wonderful, some very dedicated teachers. But I must say I was disappointed with [the high school]. They were not able to accommodate any kind of variation. There was a standard academic curriculum and everyone had to meet the same expectations. [O]ther than the time spent with the special ed teacher, there was no adaptation at all to class material. Their philosophy is that they expect, by the time a child gets through elementary school, this

should be dealt with. Any learning problems etc. should be remedied. But Mark did have a good relationship with the counsellor there.

She was able to think of changes to the the educational system, as well as other services which would greatly benefit families of children with FAS/FAE. Clearly, these services overlap many systems, and close cooperation and careful integration would be needed.

Josie:

A lot of the kids will have addictions problems, I'm sure, so there need to be good adult services. I bet a lot have issues of early trauma, abandonment etc. There need to be services available to work on these things on an ongoing basis, not just the one-off. There also need to be ongoing educational training opportunities so that as they reach a step of insight and maturity, and they're at a place in their life where they want to better themselves, that there will be some opportunities for them. And adjusted learning styles, consider that not everyone can sit in a classroom from nine to five. Maybe career counselling that recognises such things as short attention span, areas of real weakness in learning and skills, yet capitalises on the strengths that they do have, linked with the employment sector.

Paula, on the other hand, was more concerned about reforming the youth justice system. It was revealed in Chapter Six, that she felt that this system was inefficient, and that resources invested here could be more usefully channelled to children's mental health services. By providing vital services to troubled children when they are young, they can possibly avoid the youth justice system altogether.

Paula:

By the time there might be a space in a group home [at twelve or thirteen] they're far gone, you've got no control over them any more...And families that are already in crisis by that time are told they have to wait a year or two [for mental health services], with kids out of control at age four or five.

And, it is a matter of finances, but it's like not fixing a leak when it's small. Because, you know, it's not going to go away. In a year or two you're going to have a much bigger problem to deal with. And probably the kid, whatever [it was that] you could fix or help at age six, by age ten it's too late.

These proposed changes are similar to those currently advocated by Eva, Susan and Debbie. Their greatest obstacle in dealing with the schools is convincing educators that their children (especially those with so-called "normal" intelligence) may have a limit on

the level of understanding they can achieve in subjects such as mathematics, while they may continue to progress in others such as English. While long-term research on people with FAS supports this observation (Streissguth and Randels, 1988) the number of cases of FAE usually included in research is not large enough to provide conclusive results (Ibid.). However, this finding was consistent in the children included in this study, and also in research on the educational needs of individuals with FAS conducted recently in B.C. (Raymond, 1997). The parents were unanimous in their desire for more social skills (such as how to interact with peers) and life skills (for instance, how to manage money or cook a meal) to be taught in the schools.

At the high school level they believe there should be a strong emphasis on vocational skills which are relevant to their children's interests, within a program which allows individuals to continue taking academic courses (regular or modified) in areas of strength. John and Debbie have carefully researched the current special programs in the high schools, and John has insider knowledge since he has worked in this system for many years. They found that first, the number of places in these programs is far too small to accommodate the students who need them. Second, specialised programs are run by specific high schools, requiring substantial travel time to transport students. They students are taken out of their neighbourhoods and away from their friends, which have provided important supports in the past. This issue was discussed in Chapter Five, in the context of the peer group. Third, many programs with a vocational focus provide a very limited scope of possible job placements, usually unchallenging or repetitive jobs which have traditionally catered to those with low cognitive ability. Parents would like to see more opportunities geared to areas like the arts and communication which build on their children's strengths, while supporting them in areas of weakness. This is crucial, given these students' tendency to drop out of school if they become frustrated or bored. Finally the results of a large-scale study being undertaken by the Indian Health Service in Arizona (Schact, 1997), which is documenting the specific vocational needs of individuals with FAS/FAE could be used in establishing new programs, or modifying existing programs to fit the individual's needs.

Unlike Susan, Eva and Debbie, Josie and Paula were given no warnings, no "possible futures"<sup>3</sup> to help them. They were carried away in the chaotic flow of events. Even though her life is now less turbulent, Paula is still affected by her younger son's struggle with substance abuse. In describing the death of a friend's son, she displayed empathy for his family, and both relief that Brad had not suffered this fate, and fear that she could not prevent such a possibility for him.

Paula:

Actually one of the families who was there when I started [at

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<sup>3</sup> See *Anticipating the Future* in Chapter Six

the support group] and were still there when I finished... lost their son. He committed suicide ... And they just had the obituary in the paper because they just found him: he was drowned. And it just never ends, you know.

Thinking of that boy who committed suicide, that's the worst thing that could happen, and Brad's not doing so bad in comparison.

She still has to deal with the reality that no matter how much she wants to help him, she cannot save her son; he has to help himself. After a particularly upsetting visit with her son, in which she found him sick, and using drugs again, Paula wonders if the collective efforts of teachers, counsellors and herself have had any lasting effect on Brad.

Paula:

As it was he did much better at [the elementary school] where there were extra teacher aides, apart from having some excellent teachers there too. And I think because [they worked with ] the Children's Clinic, they had the use of some of the resource teachers and they had a psychologist who came through. Brad had hearing impairment and he had terrible eyesight, and even with glasses was not seeing well. Just kind of getting all those things, locating them and realising what was happening, made quite a difference. And it took the blame from him on to things that people understood. Still, I don't know what good it all did. It's often hard to, it's like suicide to see your kid on drugs. It's just an awful thing. Just really [pause] how can you not control, how can you not just go in and rescue him, you know, take him away? But you can't.... And it's just heartbreaking, you know. And at that point it's almost like you see somebody trying to jump off a bridge. It's just as desperate, just as out of control.

## 7.5 Mental Health Issues

Mental illness was an important "secondary disability" reported by Streissguth and colleagues in teenagers and adults with FAS/FAE (1996). Habbick and colleagues (1996) found that in their group of 207 people who had FAS:

Ninety-five (45.9%) had significant psychosocial problems, including 68 with attention deficit disorder and/or hyperactivity, 10 with oppositional conduct disorder, 2 with depression, 8 with psychotic features and 7 with autistic behaviour. (p. 205)

Furthermore, Famy and colleagues discovered that 60 percent of a group of adults with FAS and FAE suffered from drug or alcohol addiction, 50 percent from major depressive

disorder, and 30 percent from psychosis. (Famy et al., 1998: 553).<sup>4</sup>

Streissguth, Moon-Jordan and Clarren (1995) present three case studies which illustrate how people with FAE often receive inappropriate treatment for addiction problems. Specifically, many adults remain undiagnosed, and go unrecognised as disabled by treatment centre staff. They are accused of being disobedient and manipulative because of their inability to understand rules, their disorientation and bizarre behaviour. When the primary cognitive problems of FAS/FAE are not taken into consideration, the result is social dysfunction:

Patient 1's story is typical of patients with FAS who leave the structured environment of school and home, and try to live independently. It seems likely that the prenatal brain damage associated with FAS, rather than alcoholism per se, is the main causative factor in this man's dysfunctional life, although alcoholism further reduced his ability to cope. The emotional symptoms of worthlessness, anger suicidal ideation, and panic are typical for young men with FAS. [However], This symptomatology can be thought of as a secondary reaction to the sense of hopelessness and terror these brain-damaged people feel in trying to manage their lives independently. In this case history we can see the destructive consequences of treating the patient's secondary symptoms rather than his primary problem. (Streissguth, Moon-Jordan and Clarren 1995: 93-94)

His primary problems were fear of losing his apartment, and poor employment skills. This young man was released from the treatment centre with no follow-up plan, and his adoptive parents were unwilling to take him back into until his alcoholism was treated. He had been subjected to insight-oriented therapy which overwhelmed him with painful emotions and caused him to regress. He had been transferred to two psychiatric hospitals but was released from both without a psychiatric diagnosis. At discharge, he was left to his own devices (Ibid.).

This story is a common one. Many adolescents and adults with FAS/FAE tend to live in low income housing, in shelters, or move from relative to relative (Jenner: 1994). Because they have trouble finding and keeping jobs, and lack organisational and planning skills, they may fall behind in their rent (Streissguth, Moon-Jordan and Clarren, 1995). When these people abuse alcohol, their problems are compounded, and, like others with an intellectual disability, have many more problem behaviours (Ibid.).

While youth with FAS/FAE are an extremely vulnerable group, their plight should be seen as "the tip of the iceberg," not in the usual sense presented in the FAS literature that there are countless other alcohol-affected people out there, but as perhaps the most

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<sup>4</sup> Some had more than one diagnosis.

visible reminder of the large number of special needs children whose needs are going unmet.

Statistics collected for a large city in Saskatchewan found that

Disabled youth have higher incidence of mental illness. They have high rates of depression, those at greatest risk are disabled youth who have less visible conditions. There is a higher use of alcohol and drugs...they have fewer friends and more superficial friendships. They generally have less contact with friends...Children and youth [aged 12 to 17 are] involved with Child Protection Services... primarily because of teen/parent conflict [which] crosses all classes and the need is increasing...Approximately 12% of Saskatoon youth under 20 years of age or about 2000 are described as "youth at risk" who hang out more than three days a week downtown and are addicted to the streets although they may not live on the streets. 72% [of these youth are] Aboriginal. (SDH, 1997: 230-233)

Their reasons for leaving home, in order of priority, were family conflict, abuse, parents' substance abuse or their own substance abuse (Ibid.) Almost half of these young people had psychological counselling, and 77 percent had some police contact. While only three point four percent supported themselves by illegal activities, 33 percent report being victimised: 40 percent were physically assaulted, 30 percent were sexually assaulted and 25 percent were robbed. They listed their most important problems as drug and alcohol addiction (38.3 percent) and prostitution (13.3 percent) (Ibid, p. 233).

It is important to note that 70 percent of youth school dropouts are Aboriginal (Ibid.: 208). Furthermore,

Aboriginal youth represent a disproportionate number of the youth appearing in Saskatoon Youth Court...Results of this study also indicate that Aboriginal youth are entering the system at a younger age. Fourteen percent of Aboriginal males that appear in youth court are 12-13 years old while only eight percent of Caucasian males are 12-13 years old. Seventy-five percent of Aboriginal youth appearing in court reside in less affluent neighbourhoods in the City of Saskatoon and surrounding area. (SDH, 1997: 215)

Finally, to indicate that Jason and Brad's stories are neither outlandish, nor uncommon, street youth reported partaking in the following activities, "45% committed break-and-enters, 70% shoplifting, 23% Satanic activities, 10% pimping, 10% prostitution, 38% sold drugs, and 10% sniffed glue" (Ibid.). Child hunger and poverty, and lack of services to special needs children were identified by a number of groups in community consultations (Ibid.: 246).



While none of the younger children in the study have developed problems with substance abuse, Kate and James already have emotional problems. In the case of James, this is largely related to issues with his biological mother; Kate becomes angry and depressed in reaction to teasing and failure at school. James is receiving counselling.

Here Debbie explains how Kate has become increasingly angry and marginalised by inappropriate behaviour modification techniques.

Debbie:

I guess what's happened to her since she was four and a half that we did too, everyone tries to teach her with behaviour modification . So logical consequences, with increasing severity, and the segregation from other children, all those kinds of things. So what she's learned, what she's continually had from the world is continuously negative feedback...We try not to do that any more but it's difficult because she's disabled to the point socially where there isn't a whole lot that she does that is necessarily appropriate [which can be rewarded]. So it's really difficult to find positive situations for her, it's a real struggle.

Debbie, however, believes that counselling is useless for people with FAS/FAE.

Debbie:

[T]he only professionals we really see are in the school system, because we don't really have any other services. Counselling, that doesn't work with these kids.

She explains her reasoning.

Debbie:

A lot of people continue in therapy I think just to have someone to talk to...And I don't know if it helps the kids, but if you can afford it why not. Some people feel it's detrimental because of the fantastical thinking that they have. But I haven't seen anybody that's said it really contributes to any outcomes.

Eva believes that her sons may need counselling to help them adjust as they get older and into high school, where acceptance by peers and conforming is so important.

It was chilling to hear Susan describe her son, who is very aggressive, and large for his age in these terms.

Susan:

S: James still has a problem with separation from his birth

mom. I think they call it 'separation and loss,' the Social Services term for it, but separation definitely.

K: How does he show that ?

S: He's angry with her, and therefore he's angry with all women because they're all the same.

She also discusses some possible indications of psychosis.

Susan:

We also had, sort of a strange experience. James had been on the medication for about a week and a half and he came to me one day and he said, '...But Mom the voices are gone.' And I said, 'The voices?' And he said, 'Yeah, in my head you know, all those voices ...I don't have those anymore.'

However, one must be very careful in interpreting this behaviour. Susan explained that that James used to get very "hyper" when the radio was left on all day in the house. After he had been on the new medication, he asked his mother why they don't play the radio anymore, she said, "because it upsets you." He then replied that it was okay now because "the voices were gone."

Sacks explains how people with autism can suffer from extreme sensitivity to sound:

Temple describes her world [as a young child] as one of sensations heightened, sometimes to an excruciating degree (and inhibited, sometimes to annihilation): she speaks of her ears, at the age of two or three, as helpless microphones, transmitting everything, irrespective of relevance, at full, overwhelming volume. (1995: 254)

James has other mental health problems.

Susan:

He's not a true obsessive-compulsive behaviour, but for lack of a better term that's what they're using for it. And he has obsessions in the sense that he has, another term [the psychiatrist] uses is fixations. So he'll be fixated on something. [For instance], he will become fixated on the Titanic... he lives and breathes the Titanic. And he cannot think about anything else. It takes over his entire world..... watches, to the point where he becomes so obsessed by the watch that he will steal watches, and he's not really able to stop himself from doing that. It appears that way, but you never know with kids. We have gone through

hurricanes and tornadoes and things like that which is OK because you can find information from the library or you can do videos...[but] when you become fixated on somebody's watch or a pair of shoes,... that's very hard for you, then you have a behaviour problem.

... another thing about the obsessive-compulsive behaviour from what I've read. Like when he takes his clothes off at night time when he's going to have his shower, he leaves his pants on the floor, that's the first piece of clothing he takes off and lays it on the floor. Not scrunched up in a ball but laid out on the floor. And then he takes off his socks. And each sock has to be tucked into the pant leg. And then his shirt ... that's laid out, and then his underwear. And his underwear he kind of tucks into the pants. But he does this in the hallway in front of the bathroom, every solitary day, and he can't stop himself from doing that. And that's what people with obsessive compulsive behaviour [do], can't stop washing their hands a great deal, or can't go out because they're afraid they've left the stove on or the lights. James is not manifesting it in the normal hand-washing that some children do, he does this other thing so he is not a true one. But it's still a part of James. It's a routine that he is unable to break. And if...I'm going into the bathroom and I accidentally step on his pants lying in the hallway--Because it has to be his decision when they get picked up--so if I accidentally step on it I'm in trouble. And he can't seem to understand that I haven't done anything wrong. It's like I've invaded his space...He has to sit in the same place at the table. We can't change the wallpaper, unless we do lots and lots of talking about it and [show him] swatches of it and so on. We can't change his room.

Well, there's the stealing and we've talked about that. Some of it is because he's obsessed about something but some is purely and simply because he believes he needs something and he has been denied this. My son sort of looks at the world as a very wicked bad place. It has dealt him a really raw hand. And I'm sorry to have to say to him that yes, there have been some parts of his life that have not been very pleasant. But by and large he has done very well. But he thinks this. So, because you don't buy him something that he thinks he needs, it's his right to just take it. So stealing he has problems with. And he's big, very big for his age and big for a fetal alcohol child also, so...fighting. He has lots of fights and he's not averse to being involved in a fist fight in fact. He has no control on his temper... someone could even look at him the wrong way and that could instantly begin a fight.

...he's rude often times but doesn't realise he is....James, in his heart does not believe he's speaking rudely, that he is rude. And of course, other children do not like that. So ultimately

then they are going to 'lip him back' as he says. And then [he says]: 'Well I had no choice Mum, I had to hit him now.'

This child clearly has many problems with social interaction. However, I would separate his avid interest in certain topics from his obsessive-compulsive behaviour. They seem to be a positive trait which should be used constructively (as his mother does) rather than labelled as pathological.

## 7.6 Criminal Justice Issues

As discussed in Chapter Six, Eva has similar fears as Susan about her older son.

Eva:

In my heart I also know that if we don't intervene with Cameron, he will either end up dead at an early age, in the jail system, or totally isolated in some way. And I know that to be true, as a mother. And you've met Cameron: warm, friendly, cuddly, intelligent, all of those things. And yet he's an extremely high risk child right now. And also you throw into that that he has a facial deformity<sup>5</sup> which again, he's received some teasing and it hasn't been a big problem and probably won't be up until grade eight [when he is with a new group of peers]. And is he prepared to deal with that with the other brain damage that he has? I don't know ...I got a cold shiver the other day when I looked at him and I thought this lovable adorable child could end up in jail before he's eighteen, you know. And probably not even know how he got there.

These fears are not unfounded since many people with FAE do end up in the correctional system (Loock, 1994; Streissguth et al., 1996).

Josie pleaded for more understanding of the nature of FAE for people in the justice system.

Josie:

It would be good to see a lot more exchange between families and the justice system as well. So that when kids violate there's an understanding on the part of the justice system as to what's going on and why it's going on and therefore, the proper way to respond.

We have already heard Paula's critique of this system.

Overcrowding seems to be a significant barrier to achieving the objectives of the Youth Model and has a number of impacts including multiple transfers. These transfers lead to inconsistent

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<sup>5</sup> He had a repaired cleft lip and palate which has left some faint scarring, and his face is quite flat.

education and treatment, disruption of family relationships and continued changes to rules and expectations of youth. Standards are not in place for all aspects of youth in custody and there are inconsistencies in the degree of detail in the standards that exist and adherence to standards by staff. (Parker-Loewen, 1999: 16)

Eva discussed her opinion of the ability of individuals with FAE to understand our moral code, and the consequences of their actions.

Eva:

Because a lot of the kids with FAS/FAE are either abusers or...because they don't make those connections. You know, instant gratification, 'I needed that, or it feels good.' You get instant gratification. And if you don't connect that to your moral code because you don't understand them, why shouldn't you do it?

So that's my fear for Cameron at the moment...not making the connections. If you look at the exact way the law is, you have to form intent. So are they guilty? And again there was a case in Gustafson<sup>6</sup> where the judge basically let the guy go because he was the worst case of fetal alcohol syndrome he'd ever seen.

According to a law professor:

[The problem of FAS/FAE] has tremendous implications for how the criminal justice system handles youth in custody, says...Tim Quigley. 'It's analogous to the mental disorder defence, in the sense that we've said that people who are affected should not be punished in the usual criminal justice sense...Are these victims just as much affected by something over which they have no control, and are they deserving of punishment?' Saskatchewan Legal Aid Commission lawyer Kearney Healy says[FAS/FAE] strikes to the basic principles of criminal justice. 'The criminal justice system is based on the premise that people understand there are rules, why they have to be obeyed, and if they aren't obeyed then society has the right to come up with any number of options...All of those things are irrelevant to these kids. It's got nothing to do with good or bad--they just don't see it the same way.' (Zakreski, 1998: A2)

This passage reveals a growing awareness of FAE/FAE issues among members of the criminal justice system. However, the final two sentences imply that rules are irrelevant to those with FAS/FAE. On the contrary, people with FAS/FAE do know the difference between good and bad, right and wrong, and could probably recite a long list of rules. The problem lies in their difficulty internalising these rules. This is a result of their

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<sup>6</sup> This refers to a protest by Native people at Gustafson Lake, B.C.. The man in question was acquitted of all charges.

difficulty in processing information, and then remembering that information once it has been processed. As discussed in Chapter Two, they have particular problems in learning tasks that have a number of sequential steps. Teenagers with FAS/FAE also have extreme deficits in relating to abstract concepts and abstract language; they will not understand concepts such as rules unless they are made concrete, visible, and immediately relevant to them. By presenting the information in simple language, and small steps, ideally with visual aids or role play, it is more likely to be understood. Given the short-term memory problems, this may need to be repeated several times.

Recent research within the criminal justice system in Canada has led to the conclusion that

...When youth or adults with FAS/FE encounter the legal system, they are disadvantaged due to their communication, memory and reasoning disabilities. They may not understand their fundamental legal rights. In Canada, there has been judicial comment on FAS as a mitigating factor in sentencing and disposition. Professionals working with adolescents and adults in the legal system need to be aware of the special needs of this high risk population. (Conry, 1999)

Some factors to be taken into account include the possibility of making false confessions, and--relevant to Eva's comments above-- the ability to form specific intent:

Because of the effect of FAS on cognitive functioning, it may be that the intent necessary for a conviction under certain offences cannot be assumed or proven. A conviction requiring that the accused form specific intent in committing a crime (a requirement that the accused not only intended the act, but also intended the result to occur) is a potential issue when the accused has FAS. It cannot be assumed that an FAS accused has the planning ability or the understanding of the consequences that flow from their acts to amount to an intent that a specific result occur (Ibid.).

Furthermore, this thesis has indicated that in the case of people with FAS/FAE there are many factors, apart from cognitive ability, which must be considered. These factors are related to adoption, abuse and neglect, racism, substance abuse, and a predisposition to some types of mental illness. For instance, James sees the world as unfair, giving him the right to even the odds by taking what he needs. He feels abandoned by his biological mother, and often seeks reassurance from Susan. He is being counselled for trauma so devastating that, after five years with the same counselor, he is still unwilling to discuss the details of this event. As Susan says of her son's anguish, "I don't know if it's his adopted thinking ...or his fetal alcohol thinking." Many children with FAS/FAE have been abused or neglected. Most of the children coming into care are removed from their homes because of severe deprivation, and a recent figure

from Winnipeg says that 450 of the 1,100 permanent wards of their child-welfare system have been identified by social workers as having FAS (Roberts, 1998: A6). These factors, and the documented high rate of mental illness in the youth and adult FAS/FAE population must be strongly taken into consideration.

A common misconception is that people with FAS/FAE are unaware of the consequences of behaviour, have no conscience, and cannot show remorse. First, they do have difficulty linking their actions with the resultant consequences. The way incidents are described by the parents in this study, and in the literature by other parents, it is almost as if their children suffer a type of blackout when they are in the stressful situation of being accused of some misdeed. Streissguth, Moon-Jordan and Clarren (1995) described earlier how these individuals find strong emotions overwhelming, and often have trouble talking about their feelings. When confronted, a violent rage which seems to come from nowhere is sometimes the result (Davis, 1994).

The blackout analogy may also be the result of a peculiar type of memory, also found in autistic people, in which a situation or event can only be taken in as a whole, with all its details. In this type of “concrete situational” memory,<sup>7</sup> it is extremely difficult to extricate specific details from the whole. For instance, ‘Don’t hit your brother’ may be perceived by the affected child as “Don’t hit your brother while you’re watching television.” Therefore, in this logic, it is permissible to hit one’s brother on any other occasion, other than when sitting in the living room watching the television. McCreight (1997) explains how she is able to, over a period of days, train her son not to hit his friend when he becomes frustrated. Her first step is to help her son, piece by piece, to reconstruct the events leading up to him hitting his friend and running home. She prompts him by eliciting contextual clues which trigger his memories. She asks him: What was the weather like?, What were you wearing?, What game did you play? and other such questions to help him see the negative consequences of his actions. The next step was to get him to find another outlet for his frustrations.

Kleinfeld and Wescot eds. (1993) and McCreight (1997) provide many examples which show the caring nature and sensitivity of children with FAS/FAE. Far from showing no remorse, they are often so upset and confused by their often unintentional actions which hurt or enrage others that they become inconsolable. The apparent lack of remorse must be carefully investigated, given the above scenario regarding the difficulty understanding cause and effect. Some individuals are so hardened by early neglect, disappointments in multiple foster homes, and life on the streets that they no longer feel any attachment to mainstream society. They see nothing wrong with stealing to feed themselves according to the values of their subculture; this has nothing to do with “conscience.”(Douglas, 1995).

While the current system must change in order to meet the needs of these

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<sup>7</sup> See Appendix J

individuals, the fact that Jason was diagnosed while in jail indicates an increased awareness of this syndrome by some individuals in the criminal justice system.<sup>8</sup> Recent proposed changes to the Young Offender's Act (Parker-Loewen, 1999) do not take the nature of individuals with FAS/FAE into account. Its emphasis on alternative measures to incarceration such as sentencing circles might be helpful, as well as its increased focus on prevention. However, efforts to provide meaningful consequences for youth crime, including targeted measures for violent and repeat offenders, will have little effect on those with FAS/FAE who often do not understand the consequences of their actions, and cannot modify present behaviour based on past mistakes. Also, it is proposed that names of young offenders who are convicted and qualify for an adult sentence be published, which would increase stigmatisation of an already marginalised group.

### **7.7 Outcomes of Transracial Adoptions**

While Native people in our society often face racism, Bagley, Young and Scully (1993) contend that Native children raised by white parents often suffer specific identity problems that are related to, but which go beyond, the effects of this racism. They go as far as to say that because of the extreme racism against Native people in Canada, all Native children adopted into white families are doomed to a dysfunctional life and a disrupted adoption (Ibid):

...structural values concerning the status of ethnic minorities affect the consciousness of children (including adopted children) from such minorities, and also that families can support the identity of such children through the fostering of a "global self-esteem" which can foster ethnic pride which is sufficient in degree to defend the young person's ego in the face of ethnic devaluation offered by the larger community. [However], ...in clinical work in Canada I have encountered a number of Native children whose adoptive parents have been unable or unwilling to extend the love of their adopted Native child to that of the child's ethnicity, and the wider community of Native children to which that child is inevitably, in structural terms, linked (Bagley, Young and Scully, 1993: 84).

Bagley, Young and Scully (1993: 218) pose the question, "How do Native children 'far from the reservation' fare with white adopters?" Based on research conducted between the early 1970s and early 1980s, they conclude that there is little data to suggest that outcomes are positive. They point out the history of residential schools, forced sterilization of Native women, and the removal of many native children from their families for "alleged neglect" (Ibid).

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<sup>8</sup> A judge can order an assessment for FAS as part of a psychological assessment before a trial to determine a person's ability to stand trial, or after a person has been convicted of an offence, to help determine appropriate sentencing (Conry, 1999).



Bagley and his colleagues suggest that outcomes for adopted children should be assessed in terms of how teenagers and their parents cope with 'identity crises.' From a longitudinal study carried out in Calgary, they found that

Native child adoptions are more likely than any other parenting situation to involve problems and difficulties, and a fifth of the Native adoptees had, by the age of 15, separated from their adoptive parents. A follow-up of the adoptees two years later indicated that nearly a half of the Native adoptees, and none of the inter-country adopted group, had separated from parents because of behavioural or emotional problems, or parent-child conflict. ...The Native adoptees had significantly poorer self esteem, and were also more than three times as likely than any other group to have problems of serious suicidal ideas or acts of deliberate self-harm in the previous six months. In contrast, the non-adopted Native adolescents had adjustment profiles that were not significantly different from those of non-adopted whites. (Bagley, Young and Scully, 1993: 224)

It must be noted that the Native adoptees were being raised in Calgary, which has a small Native population. It could be argued that a Native child growing up with his or her biological parents would face the same racism in that city. The non-adopted Native adolescents were growing up on a reserve where Native people are the large majority. Therefore they would not face the same pressures that they would in the city.

Bagley and colleagues make one important exception, that children with special needs (i.e., FAS/FAE) are often rejected by remote Native communities because they lack the resources to care for them. While this points to a need for improved services, the best possible situation for these children is adoption.

Bagley et al. are taking a separatist stance regarding the adoption of Native children by non-Natives. In all other cases, they take an integrationist stance. While this issue was not fully explored in the interviews, the mothers tended to take an integrationist stance, since they made some attempts to live in multicultural neighbourhoods and/or encourage an appreciation of the child's cultural background.<sup>9</sup> Other researchers have found that children of transracial adoptions are as well adjusted as children adopted by parents of the same race or ethnicity as the child (Feigelman and Silverman, 1983; Bohman and Sigvardsson, 1990; Von Knorring et al, 1982; and Hodges and Tizard, 1989 from Bagley, Young and Scully, 1993). Furthermore, they fared better than similar children who stayed in their biological homes or went into foster care (Ibid.). Bagley, Young and Scully comment that:

These important results demonstrate, once again that although adoption cannot totally make up for early deprivation, neurological damage, or negative heredity the outcomes for adopted children are

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<sup>9</sup> Appendix I presents three approaches to transracial adoption and their implications for adoption practice.

much more favourable than in similar children who remain with a biological parent. (1993: 27)

Transracial adoptions work best when there is

...a home which provides love, warmth and security and gives the child a positive sense of racial identity in the context of [different race] playmates and a racially mixed circle of friends, is likely to provide the basis for successful adjustment in adolescence and adulthood. (Ladner, 1977, from Bagley, Young and Scully, 1993: 74)

Bagley and colleagues explain the nature of identity, ethnicity and self-esteem:

...self esteem, self-concept and identity are powerful mechanisms through which individuals understand and interpret the world around them, how they might react to these stimuli, and how they organize their lives in relation to others...How significant others interact with oneself, and give information, messages, rewards and punishments is crucially important in the formation of global self-concept, which becomes increasingly complex as the individual grows older. By adolescence global self-concept is synonymous with an individual's identity. For a minority group adolescent, such an identity is grounded in important ways in the ethnic self-consciousness a youth has. How the wider society perceives and evaluates the young person's ethnicity (e.g. skin colour and features), how the ethnic group as a collective entity views such ethnicity, and the degrees of consensus amongst minority group members on how to present one's ethnicity to the world in relation to the social and interpersonal tasks which are necessary all mean that identity is both a crucial aspect of healthy personal functioning, will vary quite markedly from group to group, and from individual to individual...An adopted child, whose ethnicity is both different from that of his or her parents, and is also to some degree stigmatized by the prejudice and oppression of the wider society has a set of identity tasks which are both unique for transracially adopted children, and are also rather complex. (p. 54)

The parents in this study tended to minimise the effects of racism on their children; they did not think it had affected them adversely. They believed in a multicultural society, and promoted interaction with people of many different ethnicities.

Josie, however, described how her intentions to involve her boys in Native cultural activities were difficult to carry out.

Josie:

K: You involved the boys in cultural activities?

J: Some, not as many as we had always intended to. Part of it was we were out of the country for so long, then by the time we got back they weren't all that interested. They probably wanted to assimilate more than they wanted to be different, and we seemed to spend all our time and energy just coping with the normal kinds of behavioural things...[W]e've taken the boys to some things [like powwows], but it almost seemed artificial at times. That we were trying, almost trying too hard to expose them to some things. And besides (and I was aware that this was happening) as they got older into their teens it had to take lower priority to dealing with the other urgent kinds of things. So I was aware that we weren't giving it all that much attention, even though we had good intentions.

In his own time, Mark began to take in interest in Native culture and spirituality. His mother thinks that these are vital to the development of Aboriginal children.

Josie:

... Aboriginal kids and young people [need] access to elders and ceremonies so they can work through this from that perspective as well. To help anchor them in something that is intrinsically meaningful to them. Something that is deep into their soul. [I think they] really mourn some sense of identity and values. In fact I think that is perhaps more crucial than anything else.

In Chapter Four it was noted that children with treaty status have access to medical care as legislated by the Indian Act. They are also eligible to apply to their band for funding of their post secondary education (Crook, 1986). When they become adults, they may also apply to live on a reserve, and then become a member of that band at age 21 (Ibid.).

Unlike Paula and Josie, Eva and Debbie have been able to expose their children to Native culture on a systematic basis through a group for parents who have adopted Native children.

Debbie:

[T]he retreat that we go on every year, we go because that group pulls together elders and others who are supportive. We want to do this. It was started a number of years ago by some families...and [a religious organisation] was the sponsor, the vehicle for how they did this. And they sort of facilitated every year. This is the only year we haven't been in about seven years. We've gone every year. And what happens is families from all over Saskatchewan come together, non-Native families with Native adopted children. And they pull together resources for the weekend. They'll bring in a group of elders, so we have cultural things that we do together. We have workshops for the kids, and

workshops for the parents. There's teen workshops where they can talk about issues. There's parent workshops where we can talk about our issues. And there's lots and lots of stuff for these families. Lots of cultural stuff, and the kids loved to go to that when they were young, they just loved it. They wouldn't miss that for the world. And when they were little all they saw there was these other brown children with white people.

Unfortunately, this program has been suspended due to the increasing costs of hiring elders and the small number of families interested in the program, because of the small number of out-of community-adoptions (Personal communication, Diana Dereski, Coordinator of SAPA, May 10, 1998). Eva and Debbie also purposefully chose to live in multicultural neighbourhoods, and Debbie is encouraging Becky's friendship with a Metis girl in the neighbourhood.

Susan, on the other hand, finds it more difficult to expose James to his Native culture. She lives in a small rural community which she admits is extremely racist, and there are no other families who have adopted Native children living nearby. Furthermore, James is afraid of Native people, probably due to some trauma he sustained in his early childhood on the reserve. His counsellor is attempting to deal with this issue.

Susan:

... If he had been living in the Native culture all the time, day after day, year after year, and season after season, things would be explained. It would become part of his life. It would be natural. But his experiences of being out on the reserve with his birth dad, he has just flashes of things and they're not making sense to him. It's making him very wary and he's scared of it. It has to come together for him where all of a sudden one day [pause] In the spring his dad had visiting privileges from the time James was a year, until he was a year and a half. I think his birth dad had him every second weekend and he went out to the reserve. James has some memories like one time he remembers them killing a rabbit. This might have been something as simple as they killed this rabbit to eat or whatever, but James maintains that they had blood that was put on their chests. Well, maybe that was a hunting thing, I'm not sure. And he has a very vivid memory of this. So that's scary stuff and he says, 'I don't need to talk about that right now Mum', and he won't. And even with [his counsellor] he won't talk about it.

It is difficult to say if these are actual memories, images he has taken from the media, scenes from his nightmares, or a scenario he has imagined. His psychiatrist has told Susan that there is some possibility that James might develop schizophrenia.

## **7.8 Reconnecting**

*Reconnecting* refers to the process in which a reconciliation occurs between

adoptive parents and their estranged children. Additionally, they may reconnect with their birth families, or increase their social network by starting families of their own, and interacting with their extended family. By this stage the adolescent or young adult children are living apart from their parents, and may have started families of their own. Parents are no longer held responsible for their children's actions by society, and life is no longer a continual round of crisis management. Parents refer to this time as a period when "things had settled down." In the case of those parents whose children were not diagnosed until their adolescence or adulthood, they must now come to terms with the fact that their children will never live up to their original expectations. They must grieve for the loss of the son or daughter that will never be, and accept the children as they are. New expectations must be established that are more compatible with "the way things are" rather than speculating on "what could be." For Paula and Josie *reconnecting* is a period of introspection, of letting go of guilt, and of reclaiming their lives. It is a time of healing, of reestablishing fractured relationships on new terms.

Many adult adoptees have a deep-seated but frustrated need to discover or actually meet a birth parent. "Pavoa argues that the search for a biological parent is a 'search for identity'" (Bagley, Young and Scully, 1993: 65). This does not mean, however, that these people suffer from psychological or "identity problems." In one study in Britain where [adoption] records are opened at age 18,

[t]he motivation for seeking such information was usually some type of kinship transition, such as getting married or the birth of a child. Of those seeking information, less than five percent were judged to be doing this in relation to a neurosis or chronic identity problem affecting mental health.(Ibid.: 66)

Researchers who surveyed 7000 adoptees found that, "...At some point (usually adolescence) almost all adoptees have a sense of detachment from their adopted family and a feeling of rootlessness..."(Cullom-Long, 1984: 1-10, from Bagley, Young and Scully, 1993: 69). It is natural, then, for adopted teens to seek out their birth families. Some contact was maintained with members of their children's biological families by Paula, Debbie and Susan from the time of the adoption. Josie was able to locate Mark's biological family when he was in his teens, and Eva has not maintained any contact with her sons' biological families.

Earlier, Paula described the negative influence that Brad's biological brothers had on him. Susan and Debbie are now wrestling with the possibility of this problem. The adoptive parents face a fundamental dilemma of striving to maintain contact with the child's family and culture, and protecting them from harmful influences, since these families may still be very dysfunctional.

Debbie:

Part of the dilemma we're having or trying to work through right now is the rest of the birth family. Hannah [An older sister] has been in contact. We've tried to get together with her twice this spring and both times I went to pick her up she was gone to [another city]. [She has]no sense of time, she's affected too. But she's in a safe place and I believe [she] would like to facilitate [maintaining contact] But these families you know that have four and five brain injured kids in them I just don't know. How do they do it? Well they don't do it with some kids. If they had four or five like Becky they could do it. But with [four or five like] Kate you couldn't do it. So, yeah, that's going to be the challenge coming up I think. I figure, a ball and chain seems very perfect [joking]. How do you think that'll go over [laughs]? If I called the police because Kate was missing, what do you think would happen? I tried to get them to do a photo I. D. on her a couple of years ago. I said, 'Do you know the Alzheimer's society does that?' But it's funded nationally, it's got nothing to do with the local police. The local police aren't interested in prevention, they're too busy out doing cops and robbers stuff. But they didn't get it. I said 'Well I would like to have her I.D.'d because she[runs away]. She didn't do a lot of running this year, but last year she bolted on us, and would take off. She never got very far but we thought we'd better start [planning for it] You know, if we had to call in the army one day and go looking for her...

Susan is also worried that James may run away with some of his birth siblings, whom he visits occasionally.

Susan:

I look at the possibility of him being with us for a very long time, unless he chooses to run away or something like that, or just saying I want nothing more to do with you. And he always has the option of going to the reserve, because he does belong to a reserve. ... My hope is though that he learns Cree and that he feels comfortable with Native people and Native culture, and if he chooses to go back to the reserve to visit, I hope he gets to know her family, I truly do. There are gaps he has to fill in and really he can't be a complete whole person, I don't think, until he fills some of that in. We see three of his half siblings, not often, but sometimes. Unfortunately, they fill his head with a lot of silly ideas like, 'Let's all run away together and find our birth mum.' Just what I need...

All the mothers in this study, however, realised that maintaining links with their culture (and sometimes) members of their biological families was vital to their children growing up with an intact identity, as a whole person. Adoptive parents cannot prevent their

reach a certain age. They can only hope that they will return one day, that they will keep that connection which was nurtured by their adoptive parents. As Josie said, parents hope that one day their children will be able to strike a balance and integrate their two worlds.

Two families, with three affected children in all, have reached the stage of *reconnecting*. Some level of contact was maintained with all the children, and new ties were created or old ones strengthened between adoptive parents and members of the biological family, as well as the extended families of their sons' girlfriends. Josie's son, Mark, is living on a reserve with his girlfriend's extended family. While he is struggling with alcohol addiction, he has remained sober for the past few months, and seems to be happy, contributing to the family by helping his girlfriend's father with his work. Paula's older son, Jason, is in jail, and his mother is rather fearful of what will happen when he is released. They have an unlisted phone number and have recently moved, not revealing their new address to him. Their younger son, Brad, lives with his girlfriend and their infant son. She will not tolerate his drinking, however, and periodically refused to let him stay at her house. At these times he moves in with his older biological sister who is probably alcohol affected herself and has three children of her own. The youngest child, according to Paula, seems to suffer from FAS or FAE. Brad is battling addictions with both alcohol and street drugs. Although both her sons are in precarious circumstances, Paula spoke of "making the most of things", of living a meaningful life by focusing on the worthwhile features of the present rather than dwelling on the anguish of the past. Josie was relieved by a recent visit with her sons, since she was able to see them in "somewhat satisfying" circumstances.

Josie:

I just saw them both last week. Mark lost a child, his first child. So that was very difficult. The baby was born at 26 weeks and lived for 48 hours. He phoned me at the birth, and the death. I went down to the reserve. His girlfriend's family is from the same reserve that Ian is from. So Mark and his girlfriend and the girlfriend's family together at the death of the infant decided to leave [the city] and go back to the reserve. So now they are all together. I went down for the wake...It was hugely traumatic, much more so than I would have imagined. It was a chance for me to reconnect with both boys, and I did. Lots of hugs and tears and talks. And I was somewhat reassured by both of the boys, to see that they were doing alright in some aspects of their lives.

Josie explains how she helped Mark find his birth family, even though she had serious reservations. He eventually went to live with them in another city, but maintained contact with his adoptive parents. More recently, he has moved to his girlfriend's reserve and seems to be doing quite well. He is trying to give up alcohol, and has kept out of trouble with the law.

Josie:

Yes, it was something he wanted to do. I think it was premature in many ways but I think he would have continued to search whether he actively searched or simply ran this through in his mind. So ...I think from this vantage point it has worked out satisfactorily. He's had a very difficult time with it but it had to come. And also here he was getting beyond the point where he was willing to conform to our expectations. So it gave him more latitude and I presume that he will, in the next couple of years, come around and find a centre point where he's more comfortable. I can see some of that happening.

Oh yeah, of course [I had concerns at the beginning]. We first got in touch with... a cousin of the mum. She was very cautious. She said the family was so dysfunctional that we should keep Mark away. That it's not a good thing. That it's just too far gone. As soon as Mark connected with them and described their lifestyle it was clear that this wasn't going to be a support for him.

Although his family was "dysfunctional," Josie knew that she could not prevent her son from taking this path to help complete his identity. She encouraged his interest in spiritual matters, hoping that this would be beneficial for him.

Josie:

Mark has been the more interested one. I can't quite mark when that started to happen, probably at about age 17 or 18. I honestly don't remember quite how or why. I think he was the more insecure of the two so it was part of his struggle to figure out where he fit and who he was. And he seemed quite naturally turned towards doing some reading, and seemed more naturally drawn to the events that we would expose him to. His family, although they are Native, they don't practice traditions very much so he didn't get it from them...[S]omehow I got him hooked up with ...[an] elder...[a]nd she spent a bit of time with him trying to guide him through some troubled times. And through a common friend he did go on a few sweats although he found them difficult, the physical aspect, so I don't think he got much spiritual out of them. But he seemed to have just a natural affinity for some aspects. He would see eagles when they were in the sky. He would readily read things into nature and to things that were happening to him. It all seemed to come quite naturally to him. I think he's quite strongly a spiritual person.

Josie hears from Mark fairly regularly, and in the spring of '97 she explained that he was going through a difficult period. Once again, she urged him to seek spiritual advice.

Josie:

He just phoned me the other night. He is fairly troubled now. He's having difficulties with his girlfriend. And every time I talk



to him I ask him if he's spoken with the elders at [his] reserve and he says no. He's reluctant to a certain extent because if he starts exploring too much it's going to be painful and hard and he's going to have to do some work. And he's not really prepared to do that work....For Mark I think it will be the closer he gets to his traditions the more strong he will become. And I see him as embracing them strongly over time as he matures.

His mother was much happier with his situation a few months later.

Josie:

And with Mark, he's got a good girlfriend, a nice girl. She's got a nice family. So he has a chance to have a period of peace, because he had relapsed. He was dry for a while, but he has relapsed...[H]e was taking a computer course, but he dropped it. I asked him about it because he was supposed to graduate this month, and he's supposed to do something else but I doubt it. [He was] physically healthy.

In Paula's case, she has maintained a close connection with Brad since he first decided to go into detox, "But then Brad decided to come back and go into detox and so we really reconnected with Brad that summer." By seeking treatment, her younger son was able to gain some insight into his problems, and begin to deal with them.

Paula:

They did an assessment with Brad [at SADAC], and a bit of counselling before he went into [the treatment centre]. They certainly talked to him about his genetic disposition to addiction and stuff but as far as I know nobody has ever said it was probably fetal alcohol, you know it's more the kind of family history of addiction.

The counselling he received at this time brought out some painful memories, and for the first time, revealed some of the details regarding the abuse Brad suffered at the hands of Jason.

Paula:

I think Brad's had some very bad experiences in Jason's hand when he was on the street. And some of that came out, Brad was in, that same summer when Jason was finally picked up Brad decided to go into detox and to the treatment centre (it was open then). We had this confrontational thing with parenting in the family week and a lot of the stuff that was going on with Jason came out. But Brad was always at risk from Jason's influence. I think less...Jason phones Brad but Brad has now got a long term girlfriend and a baby and his whole focus is a bit different. But

Brad's still really struggling with drugs and alcohol.

Although Brad is not living under ideal circumstances, Paula is hopeful for his future.

Paula:

What I hope... I'm sort of thinking my real hope is that [Jason] stays away from Brad. You know that's what I think at this point is the tragedy that Brad's at risk.

He regularly attends a local youth centre where he receives tutoring, and is motivated to stop drinking by his girlfriend and his infant son. Paula has resigned herself to the reality that she has to be grateful for the relative safety of her son, and takes joy in what she can. Thinking of that boy who committed suicide, she said that's the worst thing that could happen, and Brad's not doing so bad in comparison. She talked about going out for dinner with Brad's girlfriend and their baby and what fun they had, how he entertained them, what a little joy he was. So she is very grateful to have that in her life and believes that you have to balance the good with the bad. She sees Brad's present circumstances as an improvement over living in the streets, but is still obviously worried about him.

Paula:

The only, the thing is I think in the last year maybe he hasn't been in as dangerous situations. I guess needle use and stuff is dangerous always but he hasn't been in this sort of slum, like he has his sister's to crash at. So I'm not thinking where is he now, who's stabbing him, that kind of thing. I'm not thinking about that because[pause]He's no help either because he tells you, especially when he's coming down, all the dangerous stuff that he's got into. Because he's a ham, that's the other part of it is, he can't do this alone. He's got to have someone feeling sorry for him and amazed. So, it's a bad time.

The data for the process of reconnecting are slim since only Mark and Brad can be included. There are other cases in the literature, however which indicate that not all young people get into trouble with the law. Famy et al. (1998) point out that many individuals included as research subjects have been referred to clinics for psychiatric or severe behaviour problems. Many individuals with FAS who do not exhibit such problems would not require referral, and therefore, would not be included in these studies. Becky, for instance, would not have been referred for assessment, if her sister had not been referred because of her aggressive behaviour. If her educational needs can be met, she has a very good chance of success.

The common thread which runs through all these stories is the need for parents to let their children explore their past, in order to understand the present, and help them cope

with the future.<sup>10</sup> If adoptive parents have formed strong bonds with their children (as was clearly illustrated in *Becoming a family*), their children will not abandon them, but will return with a greater understanding of themselves.

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<sup>10</sup> The mothers perform the same tasks as they strive to understand their children and plan for their future.

## **Chapter Eight: Conclusions and Implications of the Study**

### **8.1 Introduction**

For me, as a physician, nature's richness is to be studied in the phenomena of health and disease, in the endless forms of individual adaptation by which human organisms, people, adapt and reconstruct themselves, faced with the challenges and vicissitudes of life. (Sacks, 1995: xvi)

Sacks is referring to the way in which people with neurological impairments are able to create satisfying lives by compensating for their difficulties. This relates to the participants in this study on two levels. First, children with FAE have neurological differences which cause them to perceive and process information differently from other children. Despite these differences, they must learn to adapt to learning in the classroom, and to function in society. It is the parents' responsibility to socialise these children, and, in conjunction with the schools, see that they receive the best possible education. Second, the parents must adjust to the child's disabilities, both at the personal level of taking on the identity of "parent of a disabled child,"--which for these mothers, means becoming advocates-- and creating a family life that is as close to 'normal' as possible.

This chapter revisits the explanatory model, which was introduced in Chapter Three, with the aim of illustrating the the theoretical implications of the study, highlighting its major findings, and making recommendations for future research which were raised by this investigation.

### **8.2 The Explanatory Model: Redefining Parenting**

This model illustrates the process in which mothers of children with FAE abandon previous definitions of a parent, and learn to accept their role as parents of disabled children, with all the challenges this role entails. Thus, they are *redefining parenting*. The two major sub-categories are the development of the family as it passes through a series of stages, *the evolving family*, and the transformation of the mothers' identities as they travel on their journey to *becoming advocates* for their children. While this thesis focuses on the mothers' experiences, the form their parenting takes is shaped by the unique nature of their children. Indeed, while my interview questions focused on eliciting what it was like for them to parent their children with FAE day-to-day, the mothers' answers kept returning to detailed descriptions of their childrens' behaviour, presented as anecdotes, discrete episodes in a social context. Several examples of the same type of behaviour were usually presented both to underline the consistency of the behaviour (it is predictable), and help the readers understand their children, because they can be very

difficult to understand. When compared with other individuals of the same age, the way individuals with FAE act does not make sense because it does not fit our normal frames of reference. The mothers described their children as complicated, hard to understand, and a paradox.

### 8.2.1 Carefully Chosen Words

From the earliest interviews it became clear that the strategic use of language or discourse was of profound importance for these mothers. First, carefully chosen words were used to describe and explain their children to me, as their vehicle for presenting their stories to a wider audience. Next, at different stages in the development of the family, the mothers use language for a variety of specific purposes.

Mitchell and Winslade (1997) discusses the work of Fulcher (1992) who identified four dominant themes or discourses which influence the lives of people with disabilities and their families: the medical discourse, the charity discourse, the lay discourse and the rights discourse:

[T]he politics of disability is not primarily about centralized decision-making processes, say through influential government committees, but about contests over ways of speaking in daily conversations that take place in every kind of arena. [Fulcher] shows how the policies implemented in special education are produced at all levels of political activity and that the parent-teacher interview, for example, may be subject to the same linguistic influences, or discourses, as the government committee that makes funding decisions. (Mitchell and Winslade, 1997: 167)

Service provision for people with disabilities, from this perspective, is always a political activity.

According to the medical discourse, disability is an individual physiological deficit that is a part of the individual who is physically impaired. People with disabilities come to consider themselves as deficient human beings within this discourse. Medical opinion dominates the views of the person with a disability and those of their family members when it comes to making important decisions. These decisions are constructed as technical problems rather than as social or political issues:

The person in a wheelchair is seen as having a mobility problem rather than as living in a society which is often not organized for the full participation of people in wheelchairs in social interaction. Once problem issues are defined in technical terms by diagnostic and assessment procedures under the control of medical personnel, it follows that they are resolvable only through the application of objective expert knowledge. In this way power becomes professionalised and

depoliticised. Professionals of a variety of disciplines [such as education] enter into the medical discourse when they adopt medical metaphors and use words like 'diagnosis' and 'treatment', which leads to 'knowing' what is 'in the best interests' of their clients better than they do themselves. (Mitchell and Winslade, 1997: 168)

The charity discourse is closely related to the medical discourse but operates through entities such as corporations which provide funding to people with disabilities. By portraying the disabled as pitiful and tragic figures, these groups appeal to the social conscience of the non-disabled in order to mobilise a spirit of generosity to fund services. People with disabilities, in this perspective, are viewed as objects of pity who should be grateful for what they receive. Moreover:

Claiming anything as their right or not showing the requisite amount of saintly patience easily provokes anger towards people with disabilities within this discourse because it does not fit with the position of being the recipient of charity. Employers who offer openings to people with disabilities may convey a message of expectation that the recipients should gratefully accept what they have been offered, even if the work is demeaning to the intelligence and capabilities of the person. (Ibid.)

Recipients of funds or services are always in a subordinate position to their benefactors.

Many elements of the medical and charity discourses can be found in the lay discourse, but it also contains reactions to disability such as fear, prejudice, resentment, or misplaced patronage. The social practices and manner of speaking exhibited by users of this discourse objectify and demean people with disabilities. Examples of these practices include ignoring a disabled person and speaking to their caregiver; shouting at a blind person or treating him or her like a child; labelling individuals and seeing them as disabled first and persons second; excusing disabled people from responsibility; and making fun of people with disabilities.

The rights discourse opposes the three discourses described above:

This is the way of speaking that stands upon traditions of political protest and advocates for the rights of people with disabilities as a minority group. It emphasizes liberal concerns for self-reliance, independence, and consumer wants, using strategies of confrontation and demand and challenging the conventional notions of privilege evident in the other three discourses. (Mitchell and Winslade, 1997: 169)

These discourses do not operate in a vacuum but are influenced by the economic discourse of the market, and discourses about race, gender and class.

The major premise of the narrative approach, which makes a poststructuralist analysis of power relations, is that culturally scripted stories present roles for people to fulfil, such as the long-suffering patient, grateful beneficiary, or poor, burdened, grieving parent. Discourses, therefore, rather than structures, provide the organising principle for social interaction and power relations:

For example, the medical discourse produces a relation between medical practitioner and patient. It also legitimates authority within such a relation. When people enter such a relation, they take up the positions offered in the discourse. In this way relations of power and authority are created at the local level. (Mitchell and Winslade, 1997: 170)

Consequently, these discourses have tangible effects on the lives of people with disabilities.

A positive aspect of this model is its description of power as temporary and fluid,

always subject to the changes brought about through shifts in discourse or social movements. The disability movement is an example of a social movement which gives people with disabilities opportunity to take a different stance towards the social positions offered to them by the discourses of disability. It is notable for challenges to the linguistic practices that embody discursive assumptions about disability and these challenges afford openings for persons affected by disability to re-situate their identities and relationships and developmental needs within different stories that may be more of their own choosing, less defined by others...as new ways of speaking are taken on board, new relations are forged. (Mitchell and Winslade, 1997: 170-171)

Mitchell and Winslade's primary audience are professionals who work with people with disabilities. They urge these individuals to at least be aware of the relations of power inherent in the various "systems," and challenge them to advocate for their clients whenever possible.

While some professionals did provide assistance to these families, it was up to the mothers to discover specific people whom they were able to persuade (i.e., "convert") that they were deserving of a specific service by presenting a good case. The mothers took the matter in hand, became advocates for their children, when they came to realise that they could not sit back and trust the systems to meet their children's special needs.

The mothers' process of becoming advocates is summarised below, in the context of the way they use language to create both social support for themselves, and their children. During the stage of *Becoming a Family* they begin to gather information on their children through careful observation, but often lack the words to adequately describe them to themselves and others. Without words, they lack a meaningful framework for

understanding their children. Without understanding, they lack guiding principles to help them parent these often difficult children. At this stage their efforts are unfocussed; consequently, their energy is scattered.

Mothers soon discover that normal parenting techniques needed to form emotional bonds, to teach, and to discipline children do not work with these individuals with FAE. They say that they “had a feeling that something was wrong.” This feeling of uneasiness, however, developed through careful observations made over time as described above, and in Chapters Four and Five. While mothers’ knowledge about their children could be described as intuitive, it is grounded in empirical observation: is contextual, holistic, ongoing, and comparative. Mothers, then, through “experiential knowledge” (Nowak, 1997) have become experts on their own children.

At this point in their lives, however, their quest for understanding is just beginning. Returning to the metaphor of the puzzle, they have put a few pieces of the puzzle together, but cannot yet discern the picture. In fact, they have no guide from which to work, and do not even know how many pieces they need. Even Eva, who had a diagnosis of FAE for Tim, and Susan, who was quite sure James had FAS or FAE at the time of the adoption said that they received no information, guidance, or services from professionals in health or education at that time.

Similarly, in Chapter Five, *Living Day-to-Day I: Creating the Local Community*, we learn that some of the successful strategies they have found to both manage their children’s behaviour and help them learn academic and life skills at home, were described as coming naturally or unconsciously. Again, these methods evolved, tested by trial and error, from the growing body of knowledge mothers gather about their children.

During this stage, parents try to create a support system for the child by *creating a local community*. In conjunction with this creation and maintenance of a social network for the child, mothers are performing advocacy work in which they interact with professionals in the various systems, as described in Chapter Six. Therefore, by this time, they have received a diagnosis of FAE for their children, or have had them evaluated and found that they have some features of this syndrome. Given the time and effort required to obtain an accurate diagnosis, it is reasonable for mothers to treat their children as if they have FAE whether or not they already have an official diagnosis, which is what they do.

As well as using specific language to explain their children's needs to coaches, instructors and other parents, the mothers’ narratives indicated that they avoid using the term “FAE” directly with these people. They save this medical label for their negotiations within the various systems. This indicates that they see the FAE diagnosis or label as at least potentially stigmatising in the public or “lay” discourse. Considering the recent stories in the media discussed in Chapter Two which have presented individuals with FAE as uncontrollable, asocial, and “born criminals,” these concerns are not unfounded.



Therein lies the danger of labeling these individuals; they could be treated in a stereotypical way, seen as unable to learn as children, and a danger to society as they enter their teens. This negative perspective considers people with FAS/FAE as untreatable, and therefore, any proposed services for them are viewed as a waste of time and money. Stratton and colleagues (1996) lament this defeatist attitude displayed by some professionals, and compare it to the approach to Down Syndrome several decades ago.

As they did in the interviews for this study, mothers use anecdotes to illustrate their explanations for non-professionals who they see as sharing the task of caring for their child, the adult role models discussed in Chapter Five. Furthermore, they judge their audience's level of understanding about FAE and modify their explanations accordingly. In these interactions, the parents are in control of the information and have a willing and receptive audience. These individuals, such as the recreation workers which Eva mentioned, seem genuinely grateful for any advice the mothers give them for dealing with their children. Interactions with medical and educational professionals, on the other hand, were often fraught with conflict.

### **8.2.2 Meeting Resistance**

In the category *Living Day-to-Day II: Becoming Advocates*, in the course of obtaining a diagnosis for their children, negotiating with doctors over treatment regimens and proposing alternative arrangements for their children's education to school personnel, mothers found that, in general, these professionals were uninterested in their ideas and suggestions. The intimate knowledge they had gained about their children was not valued. Their words were not heard. Interactions with these people were described as frustrating and at times futile. In the section *The Nature of Systems* in Chapter Six, mothers describe the medical, education, Social Services and justice systems as rigid, unwieldy, impersonal bureaucracies. Parents learned at first hand that the privileged professional discourse about their children had the power to silence their discourse.

Nowak (1997) explains that in an analysis of the underlying epistemology of the gate-keeping process,

attention will necessarily be drawn to questions regarding the validity of 'knowledge,' specifically, the experiential knowledge of parents about their special-needs children, juxtaposed against the bureaucratically recognized professional expertise of educational, and to a lesser degree here, medical specialists.

From the very beginning of the process by which the parent of a child with special needs tries to secure special accommodations or services for her child, she is essentially pitted against a bureaucratic system that will demand

'legitimate' documentation for her claims. This is true even in cases where the individual teachers and perhaps even the principal of the child's school all fully support the parents' interpretation of the child's needs. The system is, after all, a centralized bureaucracy and top-down decisions and allocations of this nature demand proper certification. (p.5)

Debbie described most professionals as having an ingrained, single-minded approach to problems. They were rigid thinkers, who either feared, were unaware of, or did not even contemplate change in the status quo. To base change on information coming from outside their profession was simply unthinkable. The other mothers agreed with Debbie's contention, for instance Josie described one psychiatrist as a "one treatment kind of guy."

Professionals, then, are following the medical discourse, in which professional expertise is privileged over "lay" or experiential knowledge. Doctors, teachers, and social workers are intensely indoctrinated into the specific language, and worldview of each of these professions, which perceive situations from different perspectives. Therefore, when they meet a person with FAE they recall their previous knowledge and training, and, like the rest of us, try to make sense of this person's characteristics, taking the path of least resistance, by slotting them into an existing category. Hence, many children with FAS/FAE are first labelled as ADD. Alternatively, if a professional has never encountered anyone like this before, they may unconsciously ignore any differences, and declare that "there is nothing wrong with this child," leaving the parent feeling "crazy." Given the contextual nature of these children's behaviour, it is quite possible that they will behave "normally" in a clinic or laboratory setting which is controlled and predictable. If the clinician does not believe the mother's "anecdotal" reports, he or she will base the assessment on their own observations alone.

Another factor which must be taken into consideration is the compartmentalisation of each profession, and the subspecialties within them. Once an issue has been appropriated by a particular profession, it is jealously guarded.

In Chapter Six I explained that mothers described professionals as taking on the characteristics of systems themselves, which they described as large bureaucracies. They became rigid, slow-moving, and dehumanised--dehumanised in the sense that they had to be objective and follow the rules, but also that they felt powerless to help, to effect change from their lowly position in the hierarchy. These "burnt out" workers, overwhelmed by their own, and the system's inefficacy, carry on in a sort of farce, as Paula described in the case of the youth justice system. Many workers, then, are just as much "victims of the system" as are their clients.

Many researchers have taken a structuralist approach to examining the workings of social systems such as bureaucracies. This approach will be helpful here in understanding the characteristics of bureaucracies which facilitate the maintenance of inequitable

relationships through the use of the various discourses.

Kleinman (1995), a medical anthropologist, has made a detailed analysis of the medical community. According to Kleinman, there is no question that medicine is a bureaucracy:

Now, at the close of the century, biomedicine is practiced in bureaucracies, whose effect is profound...Regulations control practice, transforming the doctor into the "provider" of a "product" that is advertised, marketed, and sold. Care is commoditized...The technical rationality of the institution, its priorities and norms, shape biomedicine. The physician is a bureaucrat; the patient is a user, a consumer of the institution's services. (1995: 37)

The technical rationality of bureaucracies refers to "generalizability, quantification, prediction, efficiency, and quality control" (Ibid., p. 33).

As well as being a bureaucracy biomedicine is professionalised:

Professional "autonomy" conflicts with bureaucratic hierarchy and control. Yet, it too sets standards that normalize training and practice. If the former, bureaucratization, routinizes efficiency, the latter, professionalization, routinizes the "quality" of care. With these two powerful masters, which concentrate the influence of the state, no wonder the patient's and family's influence on the process of care is weakened. The degree and intensity of specialization is unprecedented. The object of diagnosis, treatment, and prognosis is fragmented into a single organ system. Expert judgment is further legitimated over and against that of the generalist and the layperson. (Kleinman, 1995: 38).

He goes on to explain how medicine has become so powerful in our society that it has the power to define social, economic and political problems (such as those that lie behind the birth of children with FAE and present barriers to services) as medical problems. Consequently, voices outside the medical profession are denied privilege as legitimate contributors to the discourse. More and more phenomena come under the purview of the medical discourse; and are spoken about as if they were diseases, based in biology:

Biomedicine is not just any bureaucracy and profession, it is a leading institution of industrialized society's management of social reality. Biomedical constructions of the various forms of human misery as health problems are reinforced by societal regulations that can influence all sectors of experience, from the courts to the workplace to the household. This process of medicalization is responsible for certain of biomedicine's most controversial attributes. Biomedicine's sector of influence

continues to grow as more and more life problems are brought under its aegis. Alcoholism, other forms of drug abuse, obesity, aging, child abuse, violence--all are presently articulated as health (or mental health) conditions. (Kleinman, 1995: 39)

Once a problem is situated in the body it is individualised and removed from collective social responsibility. Furthermore, by focusing solely on disturbed physiological processes, or structural pathologies and their cures, all other doors to possible remedies are closed, all other voices are dismissed or silenced:

Medicalization leads us to search for their genetic roots, to assess other individual risk factors, and of course to quest for treatments; yet, while giving the sufferer the sick role, medicalization can stigmatize as well as protect; it can institute a misguided search for magic bullets for complex social problems; and it can obfuscate the political and economic problems that influence these behaviours. (Ibid.)

He goes on to explain the connection between observation and co-called objectivity in science. This is juxtaposed against the “subjective” reports of, for instance, mothers regarding their children:

[S]pecial place is given to the role of seeing in biomedicine, which continues a powerful influence of ancient Greek culture. Biology is made visible as the ultimate basis of reality which can be viewed, under the microscope if need be, as a more basic substance than complaints or narratives of sickness with their psychological and social entailments...The psychological, social, and moral are only so many superficial layers of epiphenomenal cover that disguise the bedrock of truth, the ultimately natural substance in pathology and therapy, the real stuff; biology as an architectural structure and its chemical associates. The other orders of reality are by definition questionable...This radically reductionistic value orientation is ultimately dehumanizing. (Ibid., 30-31)

Furthermore,

[B]iomedicine presses the practitioner to construct disease, disordered biological processes, as the object of study and treatment....The patient's and family's complaints are regarded as subjective self-reports, biased accounts of a too-personal somewhere. The physician's task, wherever possible, is to replace these biased observations with objective data: the only valid sign of pathological processes, because they are based on verified and verifiable measurements...This is a view from a depersonalized nowhere. Thus the doctor is expected to decode the untrustworthy story of illness as experience for the evidence of that which is considered authentic, disease as

biological pathology. (Kleinman, 1995: 31-32)

As outlined above, other systems such as education and Social Services share many similarities with the medical system. Their members are professionalised and bureaucratic rationality is pervasive especially in a climate of fiscal restraint.

Nowak (1997) presents the example of how parents are pitted against the school system when seeking services for a special-needs child. Parents are normally involved in drawing up an individual education plan for the child, and will be asked to attend a minimum of one review meeting a year:

Particularly in the case of children with invisible disabilities [like FAE], however, this invitation to their parents to participate at the table with teachers, educational specialists, and perhaps an administrator or two can signal the official start, not of the cooperative and constructive process the law intends, but rather, of an extraordinarily tense and oppositional series of interactions between two camps of 'experts.' At issue here...is the definition and educational implications of the child's 'difference.' (p.10)

The typical result of such meetings when the child in question is exhibiting "difficult" behaviour at school is that ways to manage problematic behaviours may be suggested to parents, when they have already tried and failed at these. When these behaviour problems are

...compounded by the fact that the medical label for the child's disability is a relatively rare one, little known (and perhaps not even accepted) by educational professionals, the stage is set for continual, though perhaps never formally declared contestation between two camps of experts: the educators, with their objective knowledge of traditional pedagogy and their collective experience of thousands of children 'who are not like this one,' and the parents, with their intensely more subjective and intimate knowledge of lived experience precisely with 'this one.' (ibid.)

As in Kleinman's analysis of the medical system, expert knowledge is "objective" while parental insights are "subjective" and devalued.

### **8.2.3 Entering the Discourse**

Nowak has a son with Asperger's Syndrome (AS) which has much in common with FAE. She describes this disability as "invisible-with-behavioural correlates" (Ibid: 6). Like FAE, it is not well known among medical experts, educational personnel or the general public. She describes how the type of disability in a child affects interactions

between that child's parents and professionals:

...an invisible disability that allows the individual to 'pass as normal' at least some of the time can and often does raise the question of 'worthiness' in the minds of those who control access to services. When the disability has socially problematic behavioural correlates...such as Attention Deficit Disorder...the parents will very likely be entering the negotiation process with a mindset greatly affected by perhaps years of felt condemnation by others regarding their parenting ability. (1997: n.7 p.6)

Nowak contends that the only way parents can have some influence on their child's treatment is to challenge the status quo by playing by rules of their own. She links the power of this bureaucracy to their careful control of access to key personnel, who have the knowledge that parents seek. If parents play by the official rules, they are maintaining the status quo:

Bureaucracies are large-scale social organizations who use gate-keeping as a strategy to keep them running in a rational and efficient manner. These gate-keepers control the access of those people at the bottom of the hierarchy (consumers of education, medicine, or other services) to those people at the top (administrators, or specialist practitioners) in order to maintain predictability. (Ibid.: 11)

Just as professionals are indoctrinated or "socialised" into the language and culture of their professions, we are socialised to accept this status quo (Nowak, 1997). Therefore challenging these systems is not easy. As I stated in Chapter Six, mothers only become advocates after they have repeatedly met with resistance, and not received satisfactory results via the official route. The collective action of parents confidently speaking up for themselves and their children, over and over again, will eventually lead to change in the system, says Nowak. It will shift the balance of power: "When parents are contesting their right for special services on the basis of an 'expertise' that may not be recognized as authoritative by the resource allocators, they are challenging this hegemony" (p. 16).

In Nowak's view, when the words of parents enter the discourse on disability within special education, they change that discourse by guiding it away from a disease model. The balance of power will have shifted ever so slightly in the parents' favour. The "story" that she wants to be told about people like her son is that they are "different" and require some accommodations, but they are neither deficient nor less deserving than so-called normal people:

... the discourse and assumptions about educational and even biological 'normalcy' that underlie special education policies [should] be opened up to the proposition that 'difference' in

these contexts need not always be equivalent to deficiency and/or pathology. (p. 11)

Sacks (1995), a psychiatrist and neurological researcher, takes a similar approach. He sees people with neurological differences as having a very different world view than the rest of us. His main argument is that these people should not be judged by our standards of normalcy, that perhaps they should not be expected to conform to our social conventions at all times and under all conditions. He is not referring to law breaking or other harmful behaviour, but the way in which some individuals are forced to speak or act a certain way which is very stressful and “unnatural” to them. He explains by quoting a pioneer in neurology:

A handicapped child represents a qualitatively different, unique type of development.[They achieve their development] in another way, by a another course, by another means...[The brain is an adaptive system]...ceaselessly adapting to the needs of the organism--its need, above all, to construct a coherent self and world, whatever defects or disorders of brain function befell it. (Vygotsky,<sup>1</sup> from Sacks, 1995: xvii)

Through his own experience of observing his patients in their social context (he refers to himself as a “neuroanthropologist”), he has come to question the assumptions that underlie the medical discourse in which he was trained:

This sense of the brain’s remarkable plasticity, its capacity for the most striking adaptations, not least in the special (and often desperate) circumstances of neural or sensory mishap, has come to dominate my own perception of my patients and their lives. So much so, indeed, that I am sometimes moved to wonder whether it may not be necessary to redefine the very concepts of “health” and “disease,” to see these in terms of the ability of the organism to create a new organization and order, one that fits its special, altered disposition and needs, rather than in the terms of a rigidly defined “norm.” (xviii)

He has learned to listen carefully to his patients’ stories, and to incorporate these into new ways of configuring medical knowledge. This recent interest in their patients’ stories or “narratives” shown by the medical community will be explored further, later in this chapter.

#### **8.2.4 Shifting the Balance**

Returning to Nowak’s argument, the only way parents can gain access to

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<sup>1</sup> *The Fundamentals of Defectology*

knowledge which can lead to services, and changes in the system is to subvert the usual procedures. They must avoid playing by the established rules. This corresponds to my concept of *playing the game*. According to Nowak, however, the primary means to dodge the rules is to ignore official channels of authority, and obtain one's information directly from the Internet. Parents can access on-line support groups and Internet sites to download and print information about their child's disability "and with this ammunition in hand, inform and even challenge obstructive personnel in the school system..."(1997: 11).

In Nowak's experience with Asperger's Syndrome, the information which leads parents to seek an official diagnosis for their child comes primarily from the Internet:

web-browsing parents of children who 'fit,' again and again, significant portions of the many descriptions of Asperger Syndrome presented on the AS website may themselves be instrumental in getting their child diagnosed, and in the course of their pursuit of that all-important diagnostic label, they may even find themselves cast in the role of educating the very medical personnel whose signatures and official diagnosis they still need to seek...This form of knowledge transmission...is a far cry from the hierarchically regulated dissemination of facts and opinions that usually links 'the layperson' to 'the medical expert' (Nowak, 1997: 12).

She goes on to delineate how Internet discussion groups are important sources of social support for their members. As mothers gain confidence in and success with their advocacy, this uplifts the entire group:

This newly discovered self confidence about the validity of their hard-won experiential knowledge, when shared with others on a listserv [sic] or email discussion group who have or are going through similar experiences, resonates throughout the entire membership of the group, and gives such parents a critical sense of belonging to a moral community that suffers and cheers with them as they proceed along the necessary bureaucratic path to keep their child's education 'appropriate.' (Ibid.)

The mothers in my study sometimes downloaded articles from the Internet which they shared with others, but they were not members of an on-line support group. Their sources of information and support were varied, as discussed in Chapter Six. All the mothers, however, relied on a specific organisation, or key individuals for specific types of information and support. And they expressed the same feeling of community which exists among parents of affected children, whether they met only once, at a conference for instance, or had met through a support group, but no longer attended meetings. It seems that the specific nature or medium of the group is unimportant, as long as it allows parents



to meet each other. These relationships are so important to parents that they will put as much time and effort into them as they can, whether or not there is a formal mechanism in place.

However, it is beneficial to have funding available to hire coordinators and other administrative staff to take the burden off the parents. The SAPA group's Executive Director and her assistant provide an up-to-date library, maintain contact with government departments, arrange for workshops and presentations, download information from the Internet, and keep their membership informed through a bimonthly newsletter.

Similarly, the medium through which the information is presented is not as important as the fact that it fits the parents' own experience, and it comes from the experience of other parents. Compare the following example with the reactions of the mothers in this study to *The Broken Cord*. One mother says she often felt very confused about her daughter's problems, but once she had a name--Asperger's Syndrome, which she discovered by browsing the web--to account for these difficulties, she says that "everything [became] so wonderfully clear" (Nowak, 1997: 13). Nowak calls this an "experience of emancipatory epiphany" (Ibid.).

### **8.3 The Moral Community**

As the mothers of children with FAE became transformed as they continued their advocacy efforts, so Nowak concludes:

Parents of children with problematically understood neurological differences ...[make] explorations via modem [which] enable them to travel around traditionally well-guarded avenues of control...While it remains to be seen how much effect their circumnavigations will have on educational [policy], the effect on their own individual consciousness can be profoundly emancipatory. (1997: 17)

Nowak calls the AS on-line support group a "moral community." Frank (1995) has outlined the nature of moral communities, which he sees as primarily communities of interpretation. Through telling their stories, and listening to the stories of others people can become transformed and can transform others. His central image is that of the "wounded storyteller":

As wounded, people may be cared for, but as storytellers, they care for others. The ill, and those who suffer, can also be healers. Their injuries become the source of the potency of their stories. Through their stories the ill create empathic bonds between themselves and their listeners. These bonds expand as the stories are retold. Those who listened then tell others, and the circle of shared experience widens. Because stories can heal, the wounded healer and wounded storyteller

are not separate, but are different aspects of the same figure.  
(Frank, 1995: xxi)

Through this storytelling meaning is created from chaos, “The wounded storyteller...is trying to survive and help others survive in a world that does not immediately make sense” (Ibid.: xiii). A “wounded storyteller” does not have to be physically ill:

Ill bodies have no special privilege as moral persons; others can become communicative bodies just as well. Illness is only one form of pedagogy that can teach the need to become a moral person. What ill people and those who are often the lowest level of their caregivers--whether nursing assistants or practitioners of poverty medicine--have in common is a kind of desperate necessity. The communicative body is a choice that derives from necessity, and the pedagogy of suffering describes this necessity. (Frank, 1995: 156)

Storytelling is a means of making sense of the world. The mothers in my study traded anecdotes about their children with others like themselves, and told these stories to professionals until they found someone who would listen. They needed to clarify the meaning of their children’s behaviour--which came when they found they fit the criteria for FAE--and also the meaning of their identities as they became advocates, which altered their relationships with professionals.

The potency of the parents’ stories come from the passion they feel for their children, and their sense of desperation. Debbie, when asked if she thought she was an expert on FAE, described herself as a “desperate mother.” Mothers are driven by their love for their children and the need to ease their own pain. Michael Dorris (1989) describes his own motivation:

..I was personally involved in the issue...single-minded...FAS was not a job for me, not a project, not a source of funding or of professional advancement. It was the definition of my son’s existence....[I was] monomaniacal...(p.229-230)

Parents who spoke in the federal government’s standing committee’s hearings into FAS (Canada, 1992), said they did not want a government agency to take over advocacy functions from the parents because it would lack their passion.

The FAS/FAE community in my model is a moral community whose members are dedicated to helping each other. Frank (1995) explains how this type of community can only occur in postmodern times,

The idea of telling one’s story as a responsibility to the commonsense world reflects what I understand as the core morality of the postmodern...The voice of the ill person is made possible by modernist medicine but it cannot be contained within modernist assumptions, particularly those

about medical professional dominance and the narrative surrender this dominance requires. A divide has been crossed into new territory, the postmodern, and we know this crossing by the new voices that are heard. As a post-colonial voice, the storyteller seeks to reclaim her own experience of suffering. As she seeks to turn that suffering into testimony, the storyteller engages in a moral action. (pp. 17-18)

The parents of children with FAE can be described as suffering an unrelenting struggle, summed up by Paula, "It just never ends." Nowak (1977) agrees:

Students with disabilities who participate in the institution of public education are indeed 'unequal' to those without disabilities, and ...there are probably few if any such students in the educational system who (along with their parents) have not experienced human suffering in the form of institutionally rooted ignorance, prejudice, or even ill will. (p.2)

The FAS/FAE community also serves important interpretive functions, allowing members to test their hypotheses, and pass their stories on to others. Likewise, mothers interpret their children's behaviour and tell others about it. It includes "converted" professionals who become longstanding members of this community. However, the mothers in my study did not present quite such a polarised view of professional-parent relationships as did Nowak.

### **8.3.1 The Case for a Special Moral Status**

The story that Nowak's (1997) group told over and over again was that their children are not deficient, they are simply different. What is the story that the mothers of children with FAE recite continuously to themselves and others? While the participants had different ways of describing FAE, the common thread was their contention that their children are socially disabled. They are impaired in their ability to adapt to and function within our society, and, therefore, deserve special protection. According to anthropologist Robert Edgerton, they are claiming a special moral status for their children.

According to Edgerton (1985), all cultures rely on the use of rules which their members must obey to maintain social order. As children, people are taught the rules of society and the penalties for breaking those rules through the process of socialisation. In Chapter Two a mother of several alcohol-affected children explained that, "Without special help,[her] children do not have the ability to follow society's rules, especially the unwritten ones..."(Lutke, 1993: 73). This impairs their ability to interact socially.

However,

No [known] society...has been able to rely solely on the internalization of rules for the maintenance of order. As

powerful as feelings of virtue and guilt can be, they are never powerful enough to ensure rule compliance by everyone; and as potent as unconscious, implicit rules are, they never cover everything that needs regulation. (Edgerton, 1985: 28)

External sanctions, such as threat of imprisonment, banishment or other punishments are enforced in every society in order to reinforce their rules.

There are, however, also rules for breaking these rules:

Rules for breaking rules are universal. For convenience, I call these rules exceptions. An exception reduces or eliminates responsibility for not following a rule that would otherwise be enforced with some sort of penalty...Exceptions to rules have a temporal dimension...[and]the extent of exemption from responsibility may also vary from minimal reduction in accountability to total exoneration, including even justification or approbation. (Ibid., 33)

Individuals in any culture can be exempted from their normal obligations if they fit into certain culturally sanctioned categories (i.e., a *special moral status*). Furthermore, these exceptions are divided into two broad types: exempting conditions (temporary and longer-lasting) and statuses. Mental illness and chronic illness are long lasting exemptions. Mental illness, however, is stigmatising for both the patient and his or her family, and this may outweigh any advantages such as allowing otherwise unacceptable behaviour (Ibid, 57-72).

Long term or chronic illness is covered by rules which circumscribe an ill person's typical behaviour. However,

Sometimes the rules are clear and known to everyone, but sometimes they are ambiguous, contradictory, or disputed...[In illnesses] that are not clearly scripted; these conditions may be argued about, and the outcome is not predetermined....As much as temporary exemptions from responsibility may benefit the exempted person, they may cause others distress, fear or anger. (Edgerton, 1985: 74)

Permanent exception is provided by a status:

[A status]...defines certain types of people as wholly or partially free from the responsibilities that bind most members of their society...certain social categories of people may break some rules that others must follow; sometimes responsibility for their rule violation is shifted to someone else [for instance, parents]. (Edgerton, 1985: 75)

A status is based on biological or cultural constraints:

In all societies, the ability of some persons to participate fully in their social and cultural world is limited by aspects of their own biology...Yet, cultures differ markedly in the extent to which they prescribe rules allowing such biological limitations to reduce responsibility. [For instance,] what societies do expect of relatively small children and elderly persons varies greatly. (Ibid., 76)

He goes on to give the example of blind people being cared for in some cultures but not in others, where they have to make a living like everyone else or are seen as an economic liability if they are “non productive.”

The mentally ill, Edgerton says, are usually taken care of in some way because

...most mental illness does not occur until late adolescence or adulthood, after a more or less normal earlier life during which a network of concerned or obligated parents, kinsmen, spouses, or children may have been established. When mental illness occurs, then it often does so after a history of social participation and worth. (Edgerton, 1985: 81 emphasis added)

People with severe mental retardation

have no such [social] history. Such persons are usually born with physical stigmata, and it is apparent early in life that their capacity to learn rules and follow them is dramatically impaired. Such persons have so little prospect of establishing social relationships or social value that one might reasonably expect societal reaction to be anything but indulgent. (Ibid.)

In the past many of these people were killed or left to die at birth. In some cultures they were given a favoured status or seen as having sacred or religious powers. Even today, infants with severe physical disabilities do not always survive despite intensive medical intervention.

In general

Because of the extent of their intellectual disability, severely mentally retarded persons are unable to comprehend or follow most of their culture's rules, from implicit conventions to moral and supernatural rules. As a result these persons require--and sometimes receive--almost total exemption from responsibility. (Ibid.)

As mentioned earlier, each society has its own way of dealing with individuals who hold these statuses:

All societies must deal with the dilemma posed by children and

by those adults who are unable to be fully productive because of developmental disabilities, illness or injury. Whether a society responds by offering a favored, indulged status or by abandoning such persons depends on a multitude of economic factors, supernatural beliefs, the interests of corporate groups, and, not inconsiderably, the affection felt toward an afflicted person. (Ibid, p. 93)

Those who are exempt from some social participation, however, may face social isolation. The lazy, arrogant, inept, or quarrelsome may be held more accountable than others, while more serious deviants such as sociopaths are treated more harshly:

While the causes of sociopathy are not yet known, sociopathic people are identifiable early in life, and the social mischief they bring about can be devastating. Sociopaths are often violent, repeatedly and impulsively breaking their societies' rules and suffering no remorse for doing so. Ordinary social pressures and appeals to morality have no effect on them. (Edgerton, 1985: 210)

In the past, these people were often exiled or executed. In our present society they are incarcerated.

All of these labels, which are related to the statuses discussed above--patient, mentally challenged, mentally ill, "like children" (as adults), and even sociopath--have at some time been applied to people with FAE. From Edgerton's analysis we can draw two major conclusions. First, the words used to describe them, and the image created by those words, can have profoundly different effects on the fate of those individuals with FAE. Second, a social history is vitally important to their well-being. This is what the parents in this study are doing by keeping their children "connected," by enabling them to become, and remain socially engaged.

Which terms, from the above, are most applicable to FAE? Which terms are the least stigmatising and provide the most benefits for these individuals in our society? Is FAE a permanent status or a long-lasting exemption? In Chapter Two, research findings were presented that confirm that FAE is, at this time, incurable and that individuals with FAE face lifelong disabilities. In Edgerton's typology this means a permanent, special status, that would require differential treatment.

### **8.3.2 Anomaly and Paradox**

An identification of a group of people as "different" should not mean treating them all the same way. Nevertheless, when people hear the terms Fetal Alcohol Syndrome or Fetal Alcohol Effects, they recall the picture of Adam from *The Broken Cord*, who was severely affected. Similarly, Sacks (1995) explains that,

The picture of “classical infantile autism” is a formidable one. Most people (and indeed, most physicians), if asked about autism summon up a picture of a profoundly disabled child, with stereotyped movements, perhaps head-banging; rudimentary language; almost inaccessible: a creature for whom very little future lies in store. (p. 246)

There are, however, high-functioning autistic individuals who have Asperger’s syndrome, who have some neurological deficits which make social interaction difficult, but lead independent lives as adults. People with Asperger’s syndrome have high IQ’s and, with great effort, are able to compensate for their deficits by learning how to behave in society. This requires intense intervention beginning in early childhood.

While autistic people are less socially engaged, and just as impaired in their social skills as people with FAE, they are not portrayed in the media as sociopaths or potential criminals. The ambivalent attitude society displays towards individuals with FAE may stem from their anomalous nature which has been portrayed vividly by the participants in previous chapters. For instance, they may be talented in some areas, but profoundly disabled in others. If one attempts to apply a clinical label, because they display behaviours and symptoms seen in others with ADD, autism, and obsessive compulsive disorder they do not fit neatly into any of these particular categories; they are anomalous.

Murphy (1987) suggests that the physically disabled hold an ambiguous status in society because they “are neither sick nor well, neither dead nor fully alive, neither out of society nor physically in it...This undefined quality, an existential departure from normality, contributes to the widespread aversion to the disabled reported by researchers (pp. 131-132). He also refers to Douglas’s analysis of anomalies (such as animals) that fall outside neat classifications: such creatures are perceived as dangerous, contaminated and disturbing, and, for instance would have taboos against their consumption. Their power, however could lead them to be either “revered or reviled.” At this point in the analysis, Murphy abandons Douglas’s model, and instead, he favours Turner’s (1967) concept of liminality. In the example of young boys undergoing puberty rituals,

The subject of passage ritual is, in the liminal period, structurally, if not physically, “invisible.” As members of society, most of us see only what we expect to see, and what we expect to see is what we are conditioned to see when we have learned the definitions and classifications of our culture. A society’s secular definitions do not allow for the existence of a not-boy-not-man...(p. 95)

Turner, however, distinguishes between the dynamic pollution accruing from one’s position between stages in a ritual, and the static pollution arising from the misclassification of persons or things. The latter, according to Turner, fit Douglas’

analysis of food taboos.

People with FAE are anomalous, “[t]heir condition is one of ambiguity and paradox, a confusion of all the customary categories” (Turner, 1967: 97). What does one do with an anomaly? It can either be treated as if it were something else (ignoring the parts that do not fit) and placing it in the most suitable category available, expanding the category to accommodate the anomaly, or a new category can be created to fit the anomaly (Edgerton, 1985; Douglas, 1995).

Because they are anomalous, people with FAE are difficult to classify. Mark was treated as if he had ADD. His other problems were ignored, and he ran into difficulties as he entered his teens. Debbie has chosen to treat Kate as if she has a traumatic brain injury. So far, this strategy seems to be working.

In Chapter Two I introduced the work of Strauss (1984), and the studies in Anderson and Bury, eds. (1988) which analyse the social dimensions of chronic illness. From the examples presented, it is clear that people with chronic illnesses such as multiple sclerosis and their families face many of the same challenges as the families in this study, both in the search for a meaningful frame of reference in which to place their experiences, and the day-to-day work of managing their lives. The mothers in this study were divided about placing FAE in the category of chronic illnesses. Debbie, Josie and Susan said FAE could be called a chronic illness while Paula and Eva disagreed strongly. Therefore, a more detailed analysis of Strauss’s (1984) model will not be pursued here. However, those who work and live with people with FAS/FAE (and affected adults) may find information and support in the literature which chronicles the personal experiences of those with chronic illnesses, and could gain allies in their struggle by extending their support network to include members of other “communities.”

Along with drawing some conclusions from Edgerton’s analysis of the nature of statuses, his research on mild mental retardation (Edgerton, 1982, 1984) can shed light on the consequences of labelling people with FAE as “mentally challenged.” Of the children in this study, only Tim has been given this designation. Tim had severe speech and language problems as a preschooler for which he received speech therapy and a place at a special needs preschool. Because of his obvious delays, he was suspected of having FAS. This led to an early evaluation and diagnosis of FAE before he entered school. At school age he was assessed as mentally challenged, with an IQ of 70 (the upper limit). Of all the families in this study, Tim’s qualifies for the most services because of his mentally challenged designation. These are enumerated in Chapter Six. He has one-to-one assistance of an aide in the classroom to help with academics, and to guide his behaviour. His curriculum is modified to his needs and abilities. It is clear to all that this child has special needs and is entitled to special treatment. Perhaps most important, the much sought after respite is available to this family. While not necessary at the moment, it may be invaluable in the future.



Previous research (Edgerton, 1967, Edgerton et al., 1984) has shown that the drawbacks of being labelled mentally challenged include people making the assumption that individuals are equally disabled in all areas, which leads to them having limited exposure to both academic and life experiences. As they near adulthood, they will likely find few employment opportunities, and those that are available may be boring and repetitive. They may be unable to live independently, and may face a great struggle in gaining an identity as adults. They may be discouraged from marrying and having a family of their own.

The children, apart from Tim, are within the low normal or normal range of intelligence. Because their disabilities are invisible they are assumed to be capable of understanding the rules and laws of society, and of functioning independently in that society. When they inadvertently break those rules they are presumed to have acted with clear intent (see Chapter Seven).

The following answers, in response to the question, "Is FAE a disability?" demonstrate that mothers in this study say that their children's primary problem is having a hidden disability. The nature of this disability--faulty cognitive functioning--leads to them being impaired in their social interactions.

Debbie:

Absolutely. They're disabled kids. They're not seen as disabled is their problem. They're absolutely disabled. And should have the same rights. If other disabled people, children are having difficulty, imagine what it's like if you don't look like you are. But they are absolutely disabled. I'd like to get a sign and hang it around my daughter's neck, 'I'm disabled.'

Susan:

But most certainly they have a disability in that their thinking processes are not the same. ...Yes, I would say a disability. It most certainly is for the children: adults too I'm sure. Disability means for me that they're not able to do what everybody else supposedly is able to do. And in many cases they can't, right? I would say, yes, a disability.

Eva:

A child or person with Fetal Alcohol Syndrome or Fetal Alcohol Effects is definitely disabled because there's permanent brain damage and it affects how they function in society. And also because, although there's no one way of describing FAE or FAS one of the common themes is that children and people with FAS/FAE don't learn by consequence and that is the way our society functions. So that

if you do this and you do this and this happens. So if you can't make those connections, if you're never able to make those connections you are extremely disabled within our society. In a different society they may not be considered disabled.

She elaborates,

Eva:

But anyways [Cameron] is quite lacking in social skills and that explains why he has trouble making really good friends, he doesn't know how to do that. He doesn't pick up on social cues at all. You just about need to take a hammer and a two-by-four and get his attention, and then often you have to draw the connections for him. That's where he's losing, he's not making the connections. And [this behaviour is] really subtle. Unless you live with this child, you know, initially you're not going to pick it up.

John provides a clear example of what is meant by the terms "poor social skills" and "social cues."

John:

And if Kate doesn't get invited to a sleepover she invites herself and has someone else come over. And then we have to supervise that. Because Kate doesn't go to sleepovers to know how to behave at one. So she has to have someone prompting her about what to do next, what's appropriate and what isn't.

While Debbie, Eva and Susan recognised their children's learning disabilities, they were most concerned about their poor social skills. They said their children were disabled in their ability to function in social situations. In retrospect, Paula and Josie, agreed with this assertion.

Eva coined the term "socially disabled" in order to concisely capture her children's primary problems. It expands the category of "disability" to include their children. Furthermore, it emphasises the social and, therefore, societal implications of their children's very specific perceptual and cognitive difficulties. Although they do not use this exact phrase, the other mothers describe their children in similar terms, as do other parents in the literature. By inventing this designation, from two unambiguous words, "social" and "disability," parents generate a new discourse on people with FAE. Starting with a fresh page, they are able to fashion their own definitions, and draft fresh strategies to engage the assistance of others in meeting their children's needs. Perhaps they will be able to avoid some of the stigmatisation carried by the FAS/FAE labels. It should be

noted that parents and some professionals are working very hard to remove this stigma, but it is difficult to combat the negative images in the media.

To return to the developmental nature of the model, as their children mature, parents must revisit their assumptions, edit their stories and resubmit them to the group for interpretation. At times, the child may show symptoms of mental illness, and this must be treated promptly. At other periods they may have attention problems which can be remedied with medication. Streissguth's model of secondary disabilities is helpful in this respect, for it warns parents of potential pitfalls. It provides a guide for intervention, showing what effects are possible under particular circumstances, but not inevitable in all cases. These negative symptoms, when framed as additional disabilities can be seen as part of the nature of FAE, rather than labels which should be applied to the child permanently.

By telling stories, then, parents contribute to the discourse on FAE and, indirectly, the discourses of both disability and medicine. By changing these discourses, they are shifting the balance of power between parents or "lay" people on one side and professionals on the other. Over time, practices in the various systems may be reformed to make them more flexible, and humane both for the workers and their clients.

Martin (1994), in her ethnographic study of concepts of health in the 1990s, points out that both "ideal bodies" and systems such as corporations, which would include the education and health care system in Kleinman's (1995) analysis, must be flexible in order to compete in today's information age:

Flexibility is an essential feature of complex systems which is seen as a valuable asset in diverse areas from computer software to workers and corporations. complex systems are never in equilibrium, they are always in flux, continuously adjusting to change: they are loosely coupled. Compared to tightly coupled systems, loosely coupled ones contain more slack and allow more variation. They can make spur-of-the-moment changes, adjustments, and innovations, and they can flexibly incorporate shocks, failures or pressures for change. (Martin, 1994: 144)

This adaptability to change becomes a valuable asset of all aspects of society once it enters the popular discourse, much as the medical model once dominated. People who are seen as rigid, needing routine and predictability, will become not only obsolete but stigmatised. According to this study, these are the attributes of people with FAE and of the environments in which they function best.

This "flexible system" is the antithesis of the systems (justice, education, health care) as they are perceived by the mothers in this study. If mothers are to be effective in changing these systems, in shifting the balance of power within existing systems, these systems must have some measure of flexibility.

#### 8.4 Towards a Cooperative Model

The parents in this study are caught in a dilemma: they rely on professionals for certain information and services, yet often find themselves in conflict with these individuals. They must tread a very fine line between being assertive and being (in the system's view) "a troublemaker." John explained that Debbie does most of the difficult negotiating with the school system because, as a teacher, he has a conflict of interest. Furthermore, while they do not wish to stigmatise their children, they are forced to seek a clinical label to name their children's problem so that it fits into narrow diagnostic categories. These are the prices they pay for the sake of their children. However, given the current pace of research, these stories are provisional.

It is important to note that despite the conflict, the disappointments and frustrations faced by parents in their encounters with some professionals, expert knowledge and practice is highly valued. Even Michael Dorris (1989) who spoke with such bitterness earlier, admits that

...these were among the most knowledgeable men and women in the world on the most crucial subject I had ever researched. They, not I, had uncovered and defined FAS, and they, not I, were the real hope of understanding and eradicating the problem. (p. 230)

It is crucial, then, for researchers, physicians, and educators to enter into a dialogue with parents, and affected individuals on a fair and equal footing. It seems that parents are taking the lead. However, given the dominance of medicine, it is important that professionals make the effort to meet them half way.

Frank's (1995) moral community includes physicians who must learn to listen to what their patients have to say:

We need to learn to think with stories [not just about them]...in this book people's illness stories are not 'data' to support various propositions that I advance. Instead, the stories are the materials that I use to model theorizing--and living--with stories....My project in clinical ethics is to move ethicists and practitioners in the direction of thinking with stories: to help professionals to recognize ill persons' stories and all they represent. The complementary project in social science might be called a sociology of witness. I seek to situate both clinical ethics and social science within a more general ethics of the body. Such an ethics develops terms of responsibility to the stories told through suffering bodies. Being responsible to these stories, thinking with them, depends on telling certain stories over and over, hearing different nuances of potential meaning as the story is told in different circumstances and at different ages of our lives. (pp. 23-24)

Compare this with a mother's appeal:

...Too often, the message given mothers [by professionals] is that a child with a problem by definition has a disturbed mother. A mother is not considered a partner in the treatment of her child, but is herself treated like a patient...It is as though considering a mother's point of view will somehow diminish their own expertise; as though listening to a mother's recommendations will constitute a challenge to their own authority. It is easier to impose one's own point of view than to consider the mother's--easier to blame the mother for not following one's than to question the advice itself....Mothers and others who work with children each have their own special expertise; each has something to contribute to a child's well-being. The opinion of each needs to be respected. (Heffner, 1978 )

When asked to prioritise his family's needs, John replied:

The biggest thing I think is to have professionals acknowledge that we know more about this than they do, that Debbie probably knows more about FAS and FAE than anyone in the province. And to listen to what she says. That is the biggest thing, because [if they listened to us] things like the respite care would be there.

Kleinman (1995) proposes a model of care which allows physicians and their patients an equal voice, through the evolution of a medical system that, by implication, can adapt to the changing needs of the environment, or "caregiving context." :

Ideally, health care institutions should be reinvented to build this vision into the structure of delivery of care. In the practical world, reinvention is infeasible. But reform is not. Such reform must be seen as a change in the values that underpin the health care system. At present, the system is concerned principally with financial gain, institutional efficiency, professional competition, and a very narrow disease-centred paradigm of practice. What is needed to change this value hierarchy is the societywide debate I have already recommended, a debate that could bring together popular and professional movements for change in a politically effective manner to focus the necessary pressures on the health care system. (p. 265)

His appeal to physicians to listen to patients' illness narratives in order to empathise with them, to enter their experiences, is similar to Frank's conception of "witnessing" the suffering of others:

For what should be the work of the physician of the chronically ill, if not this: that he is there in the experiential realm of suffering together with his patient and the members of the family. He joins them in that difficult experience to help where feasible with the medical management of the disease process. But also, at times when technical interventions are stymied, in the worst moments, he participates in the moral equivalent of what the illness experience means for patient and family. (p. 267)

Frank (1995) uses the term “frame shifting” as a conceptual aid for understanding how a dialogue can take place between patients and physicians:

The ‘pedagogy of suffering’ is the phrase I have used in my own earlier writing to describe what the ill have to teach society...By conceiving suffering as a pedagogy, agency is restored to ill people; testimony is given equal place alongside professional expertise. The pedagogy of suffering does not replace modernist medicine and supporting theories such as the sick role; rather what is opened up is the possibility for shifting between frameworks as required by responding to the ill...Postmodern illness culture, lay and medical, recognizes a need to accept suffering as an intractable part of the human condition. I understand postmodernity as a period of frameworks shifting in and out of the foreground and background. (144-145)

These frameworks correspond with Fulcher’s (1992) discourses on disability, and could also be described as worldviews. The mothers in this study, in their negotiations with professionals, shift frames or speak different “languages” as required. They are much more flexible in their approach than professionals who have been trained to think, act and speak in preconceived ways. By entering the discourse, mothers offer a space in which they and professionals can engage in empathic understanding or resonance with each other. It is up to professionals to accept this invitation.

Debbie believes that the old systems are already obsolete. Change, in her view, must be revolutionary.

Debbie:

K: ... do you have any hope of professionals and parents getting together and working together?

D: Well I do because there’s professionals that do want to work with us. The ones that aren’t able to are trapped in systems that won’t let them....I believe the public system itself is in jeopardy. If it doesn’t change to solve problems like this, it’s a dinosaur, it’s gone. Because it will happen. It’s happening faster down in the States because they’re market driven....And I wish to God I was an American sometimes. People pooh pooh their system but you know things happen

down there, they're moving ahead. But our public system is so entrenched that ...we just keep paying the bills.

Her conclusions have timely relevance for policy planning at a time when our health care system is said to be continually in crisis. Changes in this system are inevitable and may, indeed, be dramatic if the health care system, like the people in this study, is on the verge of "falling apart."

### **8.5 Recommendations for Further Research**

One of the major limits of this study is that I did not interview the children themselves. Given the high level of conflict experienced by Josie and Paula and their teenage sons, it would be interesting to discover the teenagers' views of their experiences. For instance, did Mark resent the control exerted by his parents, or was his unhappiness in school or his addiction problem a greater source of pain? I believe that a study which focused on adults and teenagers with FAE, that examined the dynamics between them and their parents, would be enlightening. Their experiences could be used to help parents of younger children modify their parenting style as the children mature into teens and adults.

The strength of this study was its close examination of the experiences of five families who are raising children with FAE. However, this small number of participants makes statistical analysis meaningless. A large-scale study of the same types of families could examine some of the factors outlined in other studies of the "caregiving context" such as the burden of care, and the value of specific types of social support. It could also validate the results of this study in a larger population. For instance, respite services were identified by the parents in this study and needs assessments as an urgent need (Tournier, 1994; MMA 1995). Another service gap is group homes and other residential services. A survey of a large number of parents which asked them to rank a list of services which other studies have identified, would enable a researcher to list these needs in order of priority. Such research findings would both complement and corroborate the information presented in this study. A report which included both detailed descriptions of day-to-day life and clear statistics to indicate these families' greatest needs would be a useful tool for policy makers and program planners. I strongly suggest, however, that any further research, or program planning, should be participatory, with parents or other caregivers directly involved as partners in the project from the planning stages to information dissemination. The next stage would include establishing, monitoring and evaluating demonstration projects.

The children in this study, on an individual basis, have much in common with some high-functioning autistic children, and with those with ADD, and other learning disabilities and behaviour problems. Research needs to be carried out to assess the feasibility of separate educational and recreational services for those with FAS/FAE who are a very heterogeneous group, as opposed to fitting them into or designing integrated

programs for similar special needs children.

Another area of possible investigation is the efficacy of support groups for children. These could be therapeutic groups. This leads to another untested issue, the contention of some mothers that counselling does not work for anyone with FAS/FAE. In Chapter Two, it was suggested that some types of therapy have shown positive results, but that research on treatment outcomes is urgently needed (Streissguth, 1994: 75). What types of counselling would be appropriate for these individuals?

The families in this study have interesting, and very specific demographic characteristics. How do their experiences differ from, say, Native families who are raising children with FAE or FAS? How do biological parents raising children with FAS/FAE cope when they do not have the “built in support” of a group such as SAPA, and can not turn to Social Services for assistance? Their experiences are likely to be different from the families in this study in some respects. Martin (1994) speculates about the differences in reactions of parents to the results of genetic counselling for Down Syndrome:

[There are]...religious, economic, moral, social grounds in which genetic knowledge about a growing fetus is interpreted. The same chromosomal ‘defect’ could be interpreted as an acceptable variation within the norm by a working-class family concerned more about physical integrity than mental acuity or as an unacceptable deformity by an upper-middle-class family far more concerned about their children scaling the heights of intelligence charts than about putting up with a minor physical abnormality....The interviews...show vividly how general cultural relevance is refracted through the particular circumstances of localized communities occupying a certain position in the larger political-economic order. (Martin, 1994: 7)

While her example can be criticized for cultural stereotyping (working-class parents may indeed want their child to go to university, and the upper-middle class family might welcome a mentally challenged child) her point is that individuals have different conceptions of what is healthy and “normal,” given their upbringing and the cultural context in which they live.

Stade’s (1995) participants reported much more stigmatisation by family members and their community than did the mothers in my study. It is difficult to make any conclusions about demographic factors affecting her participants’ experiences, since age, ethnicity etc. were not linked to individual speakers for purposes of anonymity. Her only differentiation was “mother” and “Native mother,” and the listing of several sub-themes which she associated with “cultural” factors in the Native mothers’ stories. This might be so, but nowhere does she define culture or “the Native culture” which she often uses. I do not claim that her findings are not valid, but one should realise that we all live in a



social and cultural context, and are guided by hidden values and underlying assumptions. Half of Stade's interviewees lived in the Yukon, and she reported that this group of parents faced the most severe ostracism. It should be noted that these parents had adopted or were fostering Native children. The children in the large and small cities in southern Ontario, on the other hand, adopted white, Asian or children of mixed ethnicity. Furthermore, some of these parents were also Native. Racism does not explain this rejection since the extended families and many community members were also Native. I contend that the extreme rejection faced by these families may be the high rate of alcoholism in these communities, coupled with an aggressive public education campaign, and increased case finding. An article describing these initiatives reports that Yukoners "have the highest per capita alcohol consumption in Canada" (*Toronto Star*, February 1, 1992: K6), and *The Winnipeg Free Press* featured the article "Yukon gets tough with expectant moms who drink: Women may really hit the 'bars.'" (April 9, 1995). A strong focus on the problem of FAS/FAE may have led to the blaming of families with affected children. These, and other issues need to be explored since an awareness of the social and cultural context are not only of academic interest, but are a necessary component of service development and delivery.

While suggestions were made regarding the best types of educational settings and approaches for these children, to keep them focused, help them learn, and make school enjoyable for them, no proven program has been established which will ensure successful entry into the adult world. The LSWs program sounds promising, but there are no data to support sending all affected individuals into this program. In general, there is a grave lack of long-term evaluation studies of current programs. As John said of one specific program,

John:

There's no funding for a transition piece. There's funding for this part and this piece here, but there's no transition piece to follow them. One teacher went through on the computer and looked up all the kids that had been through the ... program first semester. As of the first of June none of them were on the roll ... But there's no funding to have someone go in and follow these kids. but of twelve kids, none of them had managed to survive until June. Were they in other schools, were they back in the...program, had they switched to the mainstream program at [another high school], had they gone to [another high school], had they left town?...There's no tracking. So the only thing we're able to determine is of the twelve kids that got through none of them were in [that particular school]

If there is to be accountability, careful research and evaluation are necessary.

In Chapter Six, (see note 9, p. 176) I indicated that students, if they could be accommodated in a program, were eligible to attend school until the age of 21. Under recent amendments to *The Education Act* “Students with disabilities, between the ages three to 22 years, now have the right...to request a review of decisions made by schools [sic] boards relating to the student’s designation, placement and program. Local school boards are now required to provide students and parents with immediate access to a review process and to have written procedures available that outline the procedures (Parker- Loewen, 1999: 18). Some school boards, however, do not have formal policies for dispute resolution when parents disagree with the board’s decision (Ibid).

Most relevant to the parents in this study, Parker-Loewen, the Saskatchewan Children’s Advocate, reports that “There is still, however, no clear provision for all Saskatchewan students to be afforded the same access to a review and appeal process that disabled students can now access”(Parker-Loewen, 1999: 18). Furthermore, as the parents in this study explained, students must have one of a number of “designated disabilities” –such as “mentally challenged” –in order to be considered disabled (ibid.). While the appeal process is not perfect, it does offer an opportunity for dialogue between parents and educators which, ideally, should lead to collaborative planning for the students’ needs. Under the current system, claiming the status of disabled for their children is the only means parents have of establishing a negotiable, flexible educational plan for them. Consequently, parents devote a tremendous amount of time and energy persuading educators that their child has lifelong disabilities because of FAE, which is not recognised as a designated category for either funding or programming. Parents hope that pressure from other parents like themselves on the school system, combined with vigorous research and public education efforts of the FAS/FAE community may change this situation.

Parents complained about rigid criteria for program eligibility, and inflexible programs, which means that their children’s needs are not being met by the school system. Recall that individuals with FAE anomalous, not fitting into any known categories in our society. The school system usually approaches these children either by ignoring their disabilities, treating them as “normal” children with “problem” behaviour; or by treating them as if they had a recognised disorder such as A.D.D., then fitting them into existing programs.

Categories can also be expanded to accommodate new types of subcategories. Translated to special education programming, programs would be adapted to accommodate to meet the needs of individuals with FAS/FAE. Lastly, a new category can be created for FAE. In this case, new programs would be designed to meet the unique needs of those with FAE.

Ignoring the neurological damage, and blaming the child (or their parents) for their dysfunctional behavior in the classroom, only leads to escalation of the problem, often

culminating in a major crisis, which leads to the student being expelled, or quitting school at an early age. Similarly, giving a child an incorrect designation, will lead to inappropriate treatment and expectations being placed on the child. The child, rather than the educational interventions, will most likely be blamed for their inevitable failure. John speculated on the futility of placing Val in the Structured for Success program. A more vivid example of the harm that can result from inappropriate programming is presented by Streissguth et al. (1995) regarding alcohol treatment. The regression, despair, and inability to deal with painful emotions displayed by the young man in their case study is mirrored by Josie's description of Mark's inability to handle the emotional intensity of "family week" at the treatment centre. He acted out, was kicked out of the centre, and did not complete his treatment.

While Eva, Susan and Debbie are having some success in ensuring that some of their children's educational needs are being met, adaptations to programs or teaching approaches, or new methods of dealing with these children continue to be made on an individual, ad hoc basis. Furthermore, their greatest concern is the need for social and life skills programming to be incorporated into the regular school curricula.

Despite Debbie and Eva's assertions that conditions are becoming more favourable at their children's school as teachers and the principal climb the learning curve, incidents cited by Susan and John indicate that some educators are extremely resistant to accepting the views of parents. Since these parents have expert knowledge about their own children, and have become very well informed about FAS/FAE, their input is vital to any successful intervention with their children.

This thesis has clearly demonstrated that raising children with FAE is physically and emotionally exhausting. Respite is urgently needed for the following reasons: it is difficult to find caregivers for these children; parents and children need occasional "time out" from each other; and trained, supportive caregivers are required for teens and young adults for both short and long term placement when children and parents find it impossible to live together.

In order to remedy the shortcomings of the education and social service system (who are the usual providers of respite), additional funding and personnel are required. This will require not only new sources of funding, but a restructuring of existing programs and resource allocation. In fact, close cooperation is needed among the various systems for the provision of adequate, and integrated services. While initiatives such as the Provincial Coordinating Committee represent small steps in this direction, there is a long way to go in bringing together systems who have fundamentally different structures, goals and value systems. Change will require no less than a cultural transformation.

#### **8.4 Concluding Statement**

The purpose of this study was to describe the process of raising a child with fetal

alcohol effects (FAE) from the point of view of a specific group of adoptive parents. It was discovered that, as is reported in recent studies, people with FAE face more difficulties than those with FAS since their disabilities are invisible. Careful observation of these children in their social context, however, reveals that they are impaired in their interactions with others. Because of their anomalous nature, people with FAE are misunderstood, placed in the wrong programs, and sometimes stigmatised and rejected. Parents strive to understand their children and to explain them to others. The participants described in detail how they create a social network for their children to keep them connected socially. The day-to-day lives of these families is chronicled, and their negotiations with professionals outlined. The support network which parents build for themselves, the FAS/FAE community, sustains them emotionally, allows them to exchange information, and assists them in their advocacy efforts for their children. Teenagers and adults with FAE often become substance abusers, suffer from mental illness, and get into trouble with the law. These issues are discussed in the context of three stories, of Mark, Brad and Jason. The parents of younger children have some hope for the future of their children but also fear similar outcomes. A model was proposed which suggested the possibility of increased cooperation between parents and professionals.

Some of the interview excerpts presented in this thesis are heartbreaking, but they only scratch the surface and cannot portray the intense emotions and exhausting physical ordeal some of these parents undergo. At the time of the interviews Michael Dorris, who had been such an inspiration to these parents, died of an apparent suicide. The mothers were shocked by this event, especially Eva and Debbie, who were so pleased to have met Mr. Dorris at a conference in Seattle. Parents naturally saw their own lives reflected in this tragic event:

No one may ever know the truth regarding Michael Dorris's [sic] death; however, I can imagine that whatever it is, it was related to total heartbreak and burn out caused by so many years of broken dreams and hopes...If indeed Michael Dorris became unbalanced mentally, is it possible that any/all of us have the potential to become so weak that we could also succumb? All the more reason to openly, always support, affirm and help each other as we have stormy moments and as we see our comrades drowning in seas of anguish....Maybe Michael Dorris also felt the critical necessity of change while at the same time despairingly recognized that change isn't taking place fast enough regardless of the life investment he had provided. (Gaston, 1997).

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## APPENDIX A

### Revised Diagnostic Criteria as Proposed by the Institute of Medicine (IOM) <sup>1</sup>

#### A. Fetal Alcohol Syndrome

##### 1. FAS with Confirmed Maternal Alcohol Exposure

- a. Confirmed maternal alcohol exposure<sup>2</sup>
- b. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum and flat midface)
- c. Evidence of growth retardation, as in at least one of the following:
  - (i) low birth for gestational age
  - (ii) decelerating weight over time not due to nutrition
  - (iii) disproportional low weight to height
- d. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:
  - (i) decreased cranial size at birth
  - (ii) structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
  - (iii) neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

##### 2. FAS without confirmed maternal alcohol exposure

- b), c) and d) as above

##### 3. Partial FAS with confirmed maternal alcohol exposure

- a. Confirmed maternal alcohol exposure
- b. Evidence of some of the pattern of characteristic facial anomalies  
Either c, d, or e.
- c. Evidence of growth retardation, as in at least one of the following:
  - (i) low birth weight for gestational age
  - (ii) decelerating weight over time not due to nutrition
  - (iii) disproportional low weight to height
- d. Evidence of CNS neurodevelopmental abnormalities, as in:
  - (i) decreased cranial size at birth

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<sup>1</sup> Table 1, pp. 4-5 in Stratton, Howe, and Battaglia (1996)

<sup>2</sup>A pattern of excessive intake characterised by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, engaging in physically hazardous behaviour while drinking, or alcohol-related medical problems such as hepatic disease.

**APPENDIX A cont'd.**

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

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

Alcohol-Related Effects

Clinical conditions in which there is a history of maternal alcohol exposure<sup>3</sup>, and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are two categories which may co-occur. If both diagnoses are present, then both diagnoses should be rendered:

4. Alcohol-related birth defects (ARBD)

List of congenital anomalies, including malformations and dysplasias

Cardiac	atrial septal defects Ventricular septal defects	aberrant great vessels Tetralogy of Fallot
Skeletal	Hypoplastic Shortened fifth digits Radioulnar synostosis Flexion contractures Camptodactyly	Clinodactyly Pectus excavatum and carinatum Klippel-Feil syndrome Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic, hypoplastic kidneys Horseshoe kidneys	Ureteral duplications Hydronephrosis

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<sup>3</sup> As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.

## APPENDIX A cont'd

Ocular	Strabismus	Refractive problems secondary to small globes
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to alcohol teratogenesis remains uncertain.	

### 5. Alcohol-related neurodevelopmental disorder (ARND)

Presence of:

a. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:

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

and/or

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

**APPENDIX B**



**UNIVERSITY ADVISORY COMMITTEE  
ON ETHICS IN BEHAVIOURAL SCIENCE RESEARCH**

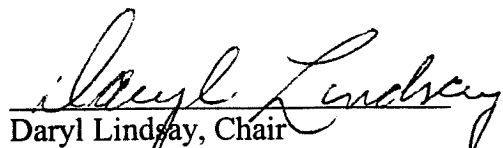
**NAME:** M. Marino [Department of Languages and Linguistics]  
(K. Burgan)

**BSC #:** 1996-117

**DATE:** April 28, 1999

The University Advisory Committee on Ethics in Behavioural Science Research has reviewed the Application for Ethics Approval for the amendment of your study "Redefining Parenting: The Process of Raising Adopted Children with Fetal Alcohol Effects (FAE)" previously titled "An Ethnographic Study of Adolescents and Young Adults with Fetal Alcohol Syndrome/Fetal Alcohol Effects and their Caregivers" (96-117).

1. Your study, as amended, has been APPROVED.
2. Any significant changes to your proposed study should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval is for 3 years from November 20, 1996.
4. I wish you a successful and informative study.

  
Daryl Lindsay, Chair  
University Advisory Committee  
on Ethics in Behavioural Science Research

DL/bjk

**APPENDIX C**

Letter of Explanation to Agencies

Dear

---

My name is Kathryn Burgan. I am a teacher who is presently enrolled in the M. A. Program in the Department of Anthropology and Archaeology, at the University of Saskatchewan. My research supervisors are Dr. Ernie Walker and Dr. Mary Marino. My thesis research will focus on caregivers' experiences of raising a child who has Fetal Alcohol Syndrome or Fetal Alcohol Effects. I believe that the knowledge and experience that caregivers can provide is equal in importance to the findings of professionals, and can provide a valuable asset in the design of appropriate services for both caregivers and individuals with FAS/FAE.

I wish to interview five sets of caregivers four times. These individuals must be caregivers (biological, adoptive, foster parents, grandparents or others who are taking a parental role) of a child who has Fetal Alcohol Syndrome or Fetal Alcohol Effect (also known as Alcohol Related Birth Defects or ARBD). The child must be aged from five to 25 and should have lived with the present caregivers for the majority of their lives. In some cases older children may be living in group homes or in other settings apart from their caregivers. All participants will be given a written and verbal explanation and a consent form (attached). Every effort will be made to protect their anonymity.

I am inquiring if you would be willing to act as a contact person who will a) identify potential participants, and b) contact these potential participants, and using the standardised explanation attached, seek to obtain their permission for you to release their names and telephone numbers to me. Those who agree to release their names and phone numbers will then be contacted by me, by telephone, and provided with an explanation of the study. Consent forms will not be signed until I have met with the participants personally and have given them a chance to ask any questions they wish.

Thank you for your consideration. I would be pleased to provide you with additional information upon request.

Yours sincerely,

.....  
(signature)

Kathryn Burgan  
B.A., B.Ed.

Phone (306) 966-4185 (univ.)

(306) 668-4342 (home)



## **APPENDIX D**

### Telephone Contact Form for Agencies

Hello (name of potential participant). I am contacting you to inform you that Kathryn Burgan, a graduate student at the University of Saskatchewan is conducting a research study. She is interested in interviewing parents and other caregivers about the experience of raising a child who has Fetal Alcohol Syndrome/Fetal Alcohol Effects. Would you be willing to let me give her your name and telephone number so she could contact you about possible participation in her study?

**APPENDIX E**  
Advertisement in Newsletter

**Dear Members of the Saskatchewan Adoptive Parents Association<sup>4</sup>**

I am looking for volunteers to take part in a **research project**. It's purpose is to record the ways in which FAS and FAE are made meaningful to caregivers of affected children. I am especially interested in your search for information and understanding (where you found information and advice and how this knowledge was shared with your own family and friends and other parents, as well as the process of obtaining a diagnosis). I will also be exploring how the experience of raising a child with FAS or FAE has affected you personally, what impact it has had upon your life. I feel this information will be helpful both to caregivers in the same situation as yourselves, and professionals who work with alcohol affected individuals.

I have included a letter approving my project from the university ethics committee. You would be given more details about the study, have a chance to ask questions, and be asked to sign a written consent form before the interviews. Briefly, I would be interviewing you in person four times (for approx. 1 hour) at your convenience. I would like the input of both caregivers if possible in the case of couples, interviewing you separately, or you could decide who will take part. I will have questions written out but I am leaving it quite open, so that you will be able to talk about issues that you think are important.

I am looking for caregivers (biological, foster, and adoptive parents as well as grandparents and others) whose child is now aged 10 to (approx.) 25. I have just begun to interview people, and will be continuing to do so through the spring and summer.

About Myself

I am currently working on my Master's degree at the U of S. I have worked in the health care system as a student nurse in an R.N. program both in a general and a psychiatric hospital. While pursuing my education degree at Nipissing university I completed a Native Education course which explored the history of the educational experience of First Nations peoples in Canada, which included a practicum in Moosonee Ontario, on James Bay. I was able to apply this valuable experience when I became a teacher in a grade 2 classroom in a band controlled school in northern Saskatchewan. It was here that I learned first hand about the characteristics and needs of children with fetal alcohol syndrome.

Thank-you for taking the time to read this. If you think you would like to participate, please give me a call. Also please pass this information on to anyone else who might be interested.

Kathryn Burgan

**email [burgan@skyway.usask.ca](mailto:burgan@skyway.usask.ca) (306) 966-4185 (office) or (306)  
6684342 (home)**

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<sup>4</sup>This was also placed in the Learning Disabilities Association newsletter, and Foster Parents Association newsletter.

## APPENDIX F

### Written Explanation for Participants

My name is Kathryn Burgan. I am a teacher who is taking graduate studies at the University of Saskatchewan. As part of my program I am studying the experience of caregivers raising a child who has Fetal Alcohol Syndrome/Fetal Alcohol Effects. My thesis supervisors are Dr. Ernie Walker and Dr. Mary Marino.<sup>5</sup>

I believe that more appropriate services can be provided in the schools and community for individuals with FAS/FAE and their caregivers if professionals are aware of the caregivers' experiences and opinions.

I would like you to participate in my study by sharing your experiences with me. There will be a series of private interviews (up to four), once a week, or once every two weeks. Interviews will be about one hour long, and will take place on a day and at a time that is best for you. I would like to interview you in your own home, but can arrange to have the interview somewhere else.

If you take part, our conversations (interviews) will remain confidential; they will be seen only by myself and, with identifying information removed, by the members of my thesis committee. Your name will never appear in any reports of the findings that may be published. However I would like to use portions of your actual words from our conversations to enrich the description of living with FAS/FAE in my thesis, and in articles from this study. You may be able to recognize the quote but others would not be able to. Every effort will be made to protect your privacy.

I would like your permission to tape record our conversations so that I may more easily recall what you have told me. However, I could take notes instead of taping our conversations during the interviews if you wish.

In order to make sure that you fit the requirements for my study and to help analyse the findings, I would also like your permission to obtain other information from you and /or the agency that contacted you. This would include things such as the age of your child, and how you are related to the child (please see attached 'demographic profile sheet') This information will be checked with you during the interviews. If this information is mentioned in the thesis or reports, again your name will not be mentioned, and your anonymity will be protected.

If you do decide to take part in the study, it is voluntary; you can refuse to answer any specific questions, can stop the interview at any time, or change it to a later date. Also, you may withdraw from the study at any time. Your refusal to participate will in no way affect the services you or your child will receive. You may not benefit directly from participation in this study, but the information may be helpful in providing better services to other caregivers and people with FAS/FAE in the future.

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<sup>5</sup> Dr. Walker and Dr. Marino were joint supervisors at the time this letter was written. Dr. Marino has been the sole supervisor since early 1998.

**APPENDIX G**

Written Consent for Caregivers

I, \_\_\_\_\_, consent to take part in a study identifying and describing the experiences of a caregiver raising a child who has Fetal Alcohol Syndrome/Fetal Alcohol Effects. I have been informed that Dr. Ernie Walker and Dr. Mary Marino are Kathryn Burgan’s thesis supervisors. I understand that the agreement allows Kathryn Burgan to interview me about my experience weekly, or every two weeks for about an hour for up to four interviews.

Before each interview, the researcher will ask my permission to tape record our conversations so that she may better recall what I have told her. If I do not wish to be tape recorded that day I understand that she will be willing to just make notes from our conversation.

I understand that my name will not appear on any of the data collection sheets or in any findings that may be reported. I understand that in all research studies involving children, such as this one, confidentiality will only be broken in the unlikely event that abuse or neglect are detected and the researcher is obliged by law to report to a child welfare authority. I understand that Kathryn Burgan wishes to use quotes from our conversations for documentation in her Master’s Thesis at the University of Saskatchewan, and for any articles which may be published arising from this study. I understand that I may be able to recognise my words, but others would not be able to.

I also understand that if that information is referred to in any report of the findings my privacy will be protected and again my name will not appear in any report of those findings.

I understand that there may be no direct benefit to me or my child. It is anticipated that the information obtained may benefit caregivers of children, adolescents, and young adults who have FAS/FAE, and affected individuals in the future.

I understand that I may withdraw from this study at any time and may choose not to answer some questions. As well, I may request that the interview or my contact with the researcher be discontinued at any time. I also understand that my withdrawal from the study or choosing not to answer any specific question will in no way affect the services provided for myself or my child who has FAS/FAE. I have been offered a copy of the written explanation and this consent form. I have been encouraged to ask questions related to any aspect of this consent form that I do not fully understand or that requires further clarification. I understand that my participation in this study is entirely voluntary. I agree to participate with full knowledge and understanding of what is intended in the study.

\_\_\_\_\_  
Name (please print)                      Signature                                      Date

\_\_\_\_\_  
Witness (please print)                      Signature                                      Date

Name of Researcher: Kathryn Burgan B.A. B.Ed.  
Supervisors: Dr. Ernie Walker and Dr. Mary Marino, Department of Anthropology and Archaeology, University of Saskatchewan.

Contact numbers:  
(306) 668-4342 (home) or (306) 966-4175 (Anth. main office)

## APPENDIX H

### Demographic Profile

**Dates: Interview**

**1.....2.....3.....4.....**

**Code Number.....**

Address.....

Phone.....

Fax.....

Email.....

Date of Birth.....Age.....Gender.....

Marital Status.....Ethnicity.....Occupation.....

Highest Level of Education.....

Emphasis /specialty if any .....

Relationship to child:

(please check)

biological parent..... adoptive parent.....foster parent.....grandparent.....

other.....(please specify).....

Child with FAS/FAE

**Code Number.....Age.....Gender.....Ethnicity.....**

If adoptive or foster parent or guardian, child's age at placement.....

If not a biological child, how many foster homes prior to placement.....

Education Level.....

Place of residency.....

Diagnosis: (please circle) suspected diagnosed FAS FAE

Mental Retardation None.....mild.....moderate.....severe.....

Attention Deficit Disorder.....

Learning Disabilities.....

Developmental Delay.....

**Other Health or Behaviour Problems**

**What are your child's strengths?**

**Child's School Placement**

- full time regular classroom.....
- regular classroom plus resource room.....
- special education.....
- residential school.....
- homeschooled.....
- Other.....

**Other Children in household**

- Age..... Gender.....
- Age ..... Gender.....
- Age..... Gender.....

**What questions or problems would you like to see addressed by researchers?**

## APPENDIX I

### Approaches to Transracial Adoption<sup>6 7</sup>

Regardless of the perspective from which transracial adoption is examined, it raises strong passions with positions being taken either for or against. Empirical arguments of what is good for children and how it seems to work out in practice are helpful, but they cannot be considered in isolation from the social, economic, political and moral context within which transracial adoption takes place. Whilst recognizing that people's views on transracial adoption do not fit into neat categories, three broad groupings are possible:

a) Those who look toward a single society in which the uniqueness of the individual is prized, and in which persons can move among cultures without being discriminated against but, on the contrary, are valued. They acknowledge the links between poverty and adoption and of the impact of racism...and the injustices that follow from this. The emphasis is on fighting racism and on recognizing the structural traps in which all disadvantaged groups are caught, irrespective of colour. They could be called internationalists/integrationists (see Ratansi, 1992; Macey, 1995).

b) Others who are more pragmatic and are concerned about the plight of the individual child for whom the alternatives may be continued fostering or transracial adoption. Their major concerns are not the social and injustices that contribute to the rise of much of childcare need, including adoption. They point to the empirical evidence concerning the well-being of transracially adopted children to support their position pragmatists/rescuers/assimilationists (Tizard and Phoenix, 1989; Bagley, Young and Scully, 1993; Gaber and Aldridge, 1994).

c) Finally, there are those who oppose transracial adoption on racial, ethnic and cultural grounds. They see identity as rooted in culture. They view transracial adoption as psychologically damaging to the [non-white] child placed with white parents. They question the basis and validity of much of the research, or question its interpretation, especially where it refers to racial identity and ethnicity. They look toward a society in which each individual is a part of his or her own culture and expect adoption to be an institution which promotes a society within which distinct cultures interact but are kept separate. (Triseliotis, Shireman and Hundleby, 1997: 160-161)

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<sup>6</sup> (Triseliotis, Shireman and Hundleby, 1997: 160-161 and 178-179)

## APPENDIX I cont'd

The practice implications of these approaches are as follows:

### **The pragmatist**

The dilemma is whether [Native]<sup>8</sup> children are going to continue to reside in residential or foster homes until social services departments put much more effort into finding [Native] families. As children wait for permanent [Native] homes, they become older and may experience unnecessary moves and consequent disruptions in relationships. We know the terrible damage to a child's capacity to trust and to form attachments which such disruptions can cause. Transracial placement can be a good alternative for these children

In spite of methodological reservations about the way notions of 'self-esteem' and 'identity' are defined, on the basis of the currently available research tools, transracial adoption does no empirically discoverable harm, if success is measured through ability to adjust and achieve in the white/[Native] world which transracially adopted children inhabit.

### **The Integrationist**

One theoretical lens through which the relevant empirical finding may be viewed is that self-esteem and group identity are conceptually separate domains. All [Native] children grow up in a dual world and are so extensively exposed to white culture that a mixed [Native]-white preference pattern may be indicative of health. A person may not have a single culture as a reference group in order to avoid identity confusion. Those who grow up transracially adopted seem to do well in 'mainstream' culture. They seem to move with some comfort within their own racial cultures. They evidence good self-esteem. They date and have friends in both worlds. Perhaps these young people will become for our society needed bridges between worlds. Transracial adoption may be an institution that promotes a society in which the individual can be a real part of more than one culture.

### **The separatist**

In terms of the cultures the children come from, transracial adoptions are failures, for most of the children so adopted are lost to the original culture. The loss of a culture's children is indeed serious for that society, and will weaken the vision of a society in which separate, strong cultures interact. The goal of adoption work must be to give every child access to to his or her community of origin. If racial identity is an integral part of mental health, then the surface adjustment of transracially adopted children disguises incomplete identity formation. If this is the case, one can anticipate that, unless the adoptive parents have been most atypical and have brought the child up in an integrated neighbourhood, the adoptee will in young adulthood experience extensive problems related to racial identity. (Ibid., pp 178-179)

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<sup>8</sup> "black" appears in the original, which means any visible minority according to the authors.



## APPENDIX J

### “Concrete-Situational” Memory

The first set of quotes are from Sacks (1995), where Sacks describes the type of memory characteristic of autistic people. The rest are from Susan, describing her son James.

...he showed a prodigious visual memory, which seemed to be able to take in the most complex buildings, or cityscapes, in a few seconds, and to hold them in mind, in the minutest detail--indefinitely, it seemed, and without the least apparent effort...It seemed to make no difference whether he drew from life or from the images in his memory. He needed no aide-memoir, no sketches or notes--a single sidelong glance, lasting only a few seconds, was enough. (pp.199-200)

Stephen also showed abilities in spheres besides the visual. He was very good at mime, even before he was able to speak. He had an excellent memory for songs and would reproduce these with great accuracy. He could copy any movement to perfection. Thus, Stephen, at eight, showed an ability to grasp, retain, and reproduce the most complex visual, auditory, motor, and verbal patterns, apparently irrespective of their content, significance, or meaning. (p. 200)<sup>9</sup>

It is characteristic of the savant memory (in whatever sphere--visual, musical, lexical) that it is prodigiously retentive of particulars. The large and small, the trivial and momentous, may be indifferently mixed, without any sense of salience, of foreground versus background. There is little disposition to generalize from these particulars or to integrate them with each other, casually or historically, or with the self. In such a memory there tends to be an immovable connection of scene and time, of content and context (a so-called concrete-situational or episodic memory)--hence the astounding powers of literal recall so common in autistic savants, along with difficulty extracting the salient features from these particular memories, in order to build a general sense and memory... Such a memory structure is profoundly different from the normal and has both extraordinary strengths and extraordinary weaknesses. Jane Taylor McDonnell, author of *News from the Border: A Mother's Memoir of her Autistic Son*, says of her son: 'Paul doesn't generalize the particulars of his experience into the habitual, the ongoing, as many (most) other people do. Each moment seems to stand out distinctly, and almost unconnected with others, in his mind...' (pp.200-201)

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<sup>9</sup> Compare this with Eva's description of Tim in Chapter 5.

## APPENDIX J cont'd

Susan:

And I'll give you an example. He was in school one day and he got into a fight with this young boy, in the French room. And they actually got down to fists... And they got called into the principal's office and Mr. \_\_\_\_ said, 'Now James there's absolutely no fighting here.' And about three days later he got into a fight with another boy out on the playground.

And James had told me that he had gotten into this fight and the next day Mr. \_\_\_\_\_ was going to be seeing him. So I had this little chat with him about fighting, and you're not supposed to do fighting and so on. And, knowing how James' mind works [laughs], when I got called to the school the next day I said, 'Mr. \_\_\_\_\_ I need James to come in and explain this to you himself. Is this OK? It's not going to do any good for you to hear this from me.'

So I said, 'James, would you tell Mr. \_\_\_\_\_ what happened in the French room.'

'Well, [this boy] he was bugging me and he called me a name and I knocked him down on the desk and he knocked me back.'

And I said, 'Is this fighting James?'

'Yes.'

'Well, what happened out on the playground?'

'Well, [a different boy] tripped me and then I pushed him and then he pushed me back.'

'Is this fighting?'

'Yes. But they're not the same Mom. One was in the French room and I was wearing my blue shirt and I had on my blue jeans and [that boy] had his green shirt on and his black pants. And he called me a name. With [that other boy] and I ...[he] was wearing his black snow suit and I was wearing my blue snow suit, and he tripped me.'

[we both laugh]

And there was not, there was nothing, there was no correlation between the two whatsoever.

And Mr. \_\_\_\_\_ just looked at him and said, 'I think I'm getting the picture Susan.'

...so he hasn't got that memory bank that we all have to draw back on. You know how your brain works... You go back to this memory bank that says, 'last time this happened'... James doesn't have that because he's seeing, I think, things in pictures. . . . So he would have to have a fight again in the French room, wearing the same clothes, and the other child had to wear the same clothes in order to ... for himself, to stop and say, 'Oh, I wasn't going to fight anymore.' But the two instances, as far as he is concerned, are not similar.

Susan:

Well, the observation part, [James] can see things that I've never seen in my whole life. He's been really good for our family. ... He almost has a picture in his head. If he saw a butterfly [and then drew it], I would not question what that butterfly looked like. My memory would never be as good as his... And he could actually put that down on paper, and bring that picture back to recall on another occasion to do that again. He may not be aware of 17 cars that are out there behind, beside, that butterfly [that could put him in danger] but that particular item (and he will have that in detail)...he's able to draw that.

## APPENDIX K

### Sample Interview Guide

#### EXAMPLES OF BROAD OPENING QUESTIONS OR STATEMENTS

“Will you tell me what your life has been like living with \_\_\_\_\_ (name of child who has FAS/FAE)?”

“Please tell me about your experiences of living with \_\_\_\_\_ your child with FAS/FAE.”

“What is it like for you to raise a child with FAS/FAE?”

Questioning was informal, allowing the participant to lead the conversation. However, the following types of questions were asked if the participant did not volunteer the information:

1. How would you describe your child?
2. Describe the process you went through to discover that your child has FAE.
3. What does the diagnosis mean to you?
4. Please tell me about you and your family’s day to day life with \_\_\_\_\_ (child).
5. What kind of help and support have you received from
  - 1) Professionals?
  - 2) Friends?
  - 3) Family?
  - 4) Community?
6. Do you belong to, or have you ever belonged to a support group?
7. Please describe your experience with this group.
8. What are the most difficult problems you face raising \_\_\_\_\_ (child) day-to-day?
9. What strategies have you found that really help \_\_\_\_\_ (child) learn better at school; to make life easier at home?
10. What advice would you like to give other parents like yourself?
11. a) What information have you found most useful?  
b) What information would you like to know?