

DIAGNOSING FETAL ALCOHOL SYNDROME: ECONOMIC AND POLICY
IMPLICATIONS

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Abstract

Fetal Alcohol Syndrome (FAS) is a range of physical and neurobehavioral disabilities that is the result of maternal alcohol consumption during pregnancy. FAS and its related disabilities are significant socio-economic concerns to Canadians and is thought to be prevalent in Saskatchewan. Often, diagnosis is necessary for access to services that will improve outcome of affected individuals and their families. This thesis was designed to determine an estimate of some economic costs associated with Fetal Alcohol Syndrome and its related disabilities to Saskatchewan and to determine why (and if) FAS is underdiagnosed in Saskatchewan. Economic costs to social services, justice, education, and health were estimated using provincial budgets and estimated prevalence rates of Fetal Alcohol Syndrome and its related disabilities. A case-based method was also used. The economic estimates suggested that prenatal alcohol exposure is costing the province of Saskatchewan \$41.1 million per year. More specifically, costs to social services, justice, education, and health were estimated to be \$5.9 million, \$17.6 million, \$0.26 million, and \$20.3 million, respectively. Based upon population estimates, the total costs of FAS and its related disabilities to Saskatchewan may reach \$XX million by the year 2021.

Physicians, especially general practitioners, are often the first line of contact for FAS-affected individuals and their families. Previous data suggest that physicians may not feel comfortable caring for affected individuals and their families, nor do they have the knowledge necessary to make effective and reliable FAS-related diagnoses or referrals for diagnosis. Study 2 was designed to determine the knowledge and attitudes of Saskatchewan general practitioners with respect to FAS and its related disabilities. Survey questions were based upon a survey performed in 1992. Data suggest that FAS is underdiagnosed in Saskatchewan and that general practitioners do not feel comfortable caring for affected individuals or their families. Data also suggest that Saskatchewan general practitioners do not have adequate knowledge to make effective FAS diagnoses or referrals, although some report that they have diagnosed FAS. There were no significant effects of place of practice, university appointment, or graduation year on knowledge about FAS. Finally, data suggest that, in a ten-year period, knowledge levels with respect to FAS have not increased but the number of physicians making referrals for diagnosis has increased.

Together these data suggest that FAS costs Saskatchewan a significant number of dollars and that effective intervention programs may mitigate some of these costs. However, services are based upon need, and need is defined through comprehensive diagnostic assessments, but physicians need more education and training with respect to the diagnosis of FAS and its related disabilities.

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This MBA thesis (and the MBA itself) was not the work of one. It was possible because, first and foremost, of the support and the help of my husband, Brian. He watched me calculate late into the night, held a screaming baby so I could finish writing a section, cooked and did the dishes so many times so I could study for an exam.....never complained that I had endless hours of homework to do.

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I am proud of this MBA – the world of business is very different for a Scientist and I am happy that I was able to pull it all together. I look forward to a career where I can apply the skills I learned about, developed, and refined during my MBA training.

Dedication

For my Nan

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1.0 Introduction to Fetal Alcohol Syndrome and Fetal Alcohol Effects

1.1 Purpose

Fetal Alcohol Syndrome and its related disabilities have significant costs to society that can be reduced with access to appropriate services and resources. Access is dependent upon an accurate diagnosis, but data suggest that Fetal Alcohol Syndrome is underdiagnosed. Thus, this two-part thesis was designed to:

1. determine an estimate of some economic costs associated with Fetal Alcohol Syndrome and its related disabilities to Saskatchewan and
2. determine why (and if) Fetal Alcohol Syndrome is underdiagnosed in Saskatchewan

1.2 History of Prenatal Exposure to Alcohol

For centuries, it has been recognized that alcohol consumption during pregnancy is associated with abnormal fetal growth and development. Aristotle wrote in *Problemata* "Foolish, drunken, or harebrain women most often bring forth children like unto themselves" and references to the negative effects of alcohol on fetal outcome can be found in biblical passages (e.g., "Behold, thou shalt conceive and bear a son: And now, drink no wine or strong drink. *Judges 13:7*). Findings by physicians in 18th and 19th century England also suggested that that there was knowledge that alcohol consumption during pregnancy presented a risk for poor pregnancy outcome. (Warren and Bast, 1988) However, this information was lost over time and, in fact, during the 1960's, medical professionals and pregnant women were advised that alcohol might help to reduce some of the adverse effects of pregnancy. (Fuchs *et al.*, 1967) At present, it is commonly accepted that prenatal exposure to alcohol has significant negative effects on fetal growth and development.

Despite early knowledge of the adverse effects of alcohol consumption during pregnancy on fetal outcome, it was not until the late 1960's and early 1970's that a common pattern of birth defects was reported in children born to alcoholic women, first in France (Lemoine *et al.*, 1968) and then in the United States. (Jones *et al.*, 1973) In their landmark manuscript published in *The Lancet*, Jones and Smith coined the term "Fetal Alcohol Syndrome" to describe the specific constellation of defects observed in children prenatally exposed to alcohol. (Jones and Smith, 1973) The implementation of public policy followed, and the first public alert from the United States Department of Health, Education, and Welfare regarding the possibility of hazards associated with drinking alcohol during pregnancy was issued in 1977. In 1981, the Surgeon General of the United States advised pregnant women to avoid alcohol completely, which remains the current message regarding alcohol use during pregnancy.

1.3 Definition of Fetal Alcohol Syndrome

Fetal Alcohol Syndrome (FAS) is a medical diagnosis that refers to a specific pattern of craniofacial, growth, and neurobehavioral anomalies associated with the use of alcohol during pregnancy.

1.4 Definition of Fetal Alcohol Effects

In order to receive a diagnosis of FAS, individuals must meet specific diagnostic criteria (see section 1.5: Diagnosis of FAS). However, it is possible for patients to meet some, but not all, of the criteria. Fetal Alcohol Effects (FAE) is the term used to describe the presence of some, but not all, FAS characteristics when prenatal exposure to alcohol has been confirmed (This term is also used occasionally when prenatal exposure to alcohol cannot be confirmed).

Most often, FAE is associated with neurobehavioral deficits that are just as severe as those characteristic of the full-blown Fetal Alcohol Syndrome. Usually, however, individuals diagnosed with FAE do not have the unique craniofacial profile associated with FAS. This is probably due to differences in maternal alcohol consumption

patterns, amounts, and duration of exposure during pregnancy. Organs and systems affected are the ones that are developing *in utero* during the time of alcohol exposure. Thus, a binge-like pattern of consumption that did not occur during the short gestational window where craniofacial development occurs will not result in abnormal facial features. For an illustration of timing of fetal organ development, please refer to Exhibit 1.1.

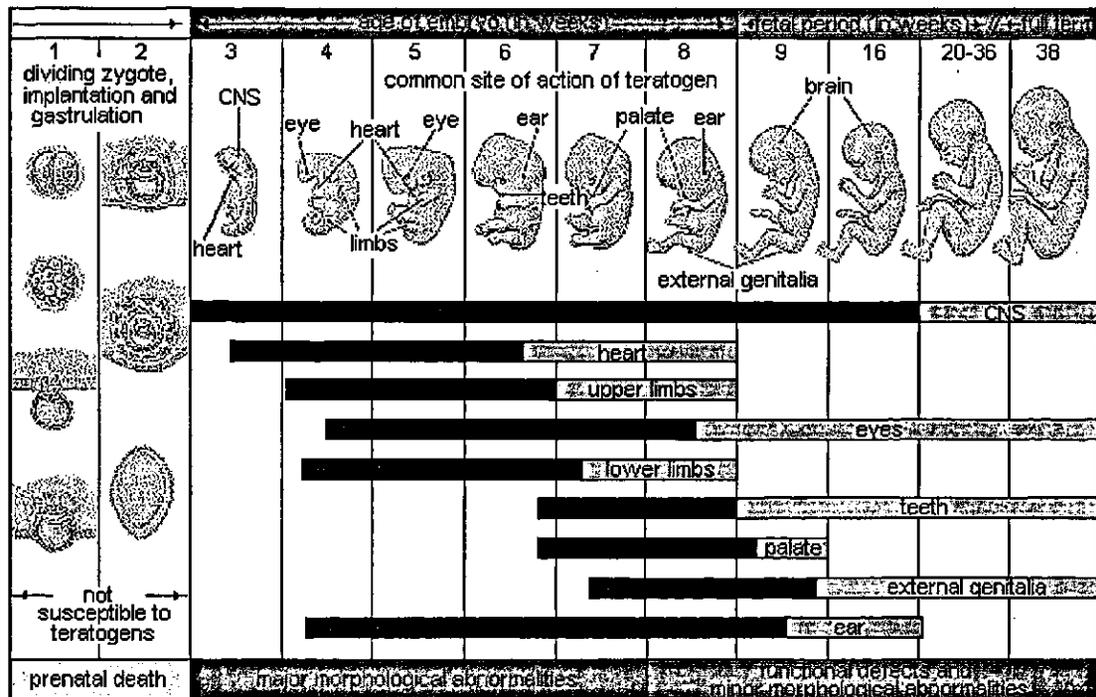


Exhibit 1.1: Fetal Organ Development. This exhibit illustrates human embryo and fetal development during gestation. Light blue bars indicate periods when organs are most sensitive to damage from alcohol. What is affected by alcohol during fetal development will depend on what is developing at the time of exposure. [Adapted from Human Biology by Starr and McMillan (Starr and McMillan, 2000)]

FAS is characteristic of mothers who abused alcohol throughout pregnancy while FAE may result from more intermittent binge-like consumption patterns. Recent data in animal models designed to study fetal alcohol effects parallel these findings, suggesting that alcohol exposure during development can produce behavioral deficits in the absence of the more severe effects on brain and body growth typically associated with fetal

alcohol syndrome. (Tattoli *et al.*, 2001) Human studies report similar data. (Mattson *et al.*, 1997)

It must be emphasized that it is misleading to think of FAE as a lesser form of FAS, since affected individuals often have CNS and neurobehavioral deficits that parallel those of FAS individuals, although they may lack the associated facial dysmorphism. Thus, individuals with FAE are often just as disabled as those diagnosed with the full syndrome (for example, see Figure 1.1).

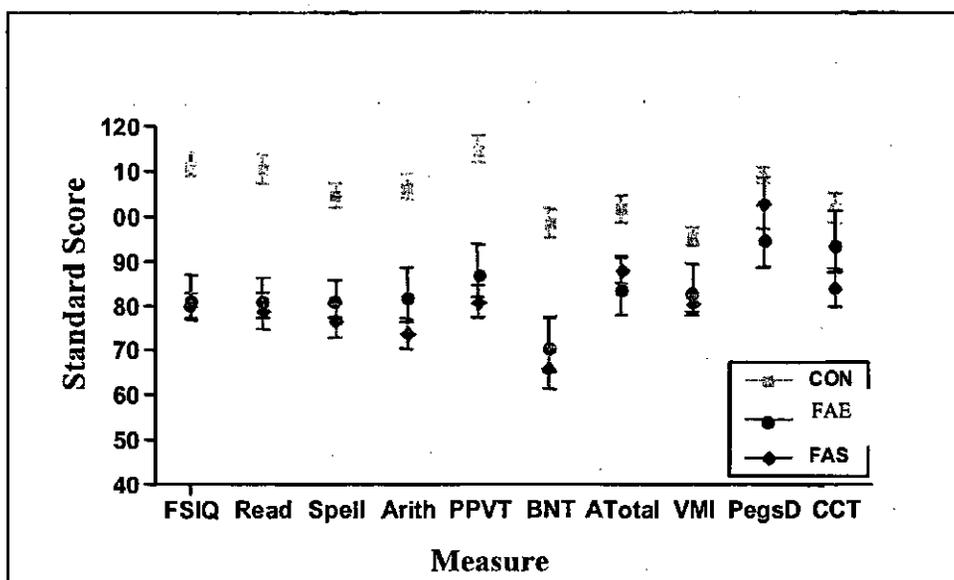


Figure 1.1: Neuro-Psychological Performance Associated with Fetal Alcohol Syndrome and Prenatal Alcohol Exposure. Neuropsychological scores of individuals with FAS, FAE, and normal controls who had not been prenatally exposed to alcohol (CON). Both groups exposed prenatally to alcohol (FAS, FAE) had lower performance scores in all tests. (FSIQ = full-scale IQ test, designed to measure overall intelligence; Read = Reading; Spell = Spelling; Arith = Arithmetic; PPVT = Peabody picture vocabulary test, a test of receptive vocabulary; A Total = a measure from the California verbal learning test (CVLT) of overall learning on a 5-trial acquisition task; VMI = visual-motor integration, a test requiring the child to copy line drawings; PegsD = a measure of fine-motor speed and dexterity using a grooved pegboard and a dominant hand; CCT = children's category test, a measure of nonverbal problem solving. (Mattson and Riley, 1998)

1.5 Effects of Prenatal Alcohol Exposure

There is a continuum of alcohol's effects (Exhibit 1.2) and the diagnosis of FAS is for individuals at the severe end of the continuum.

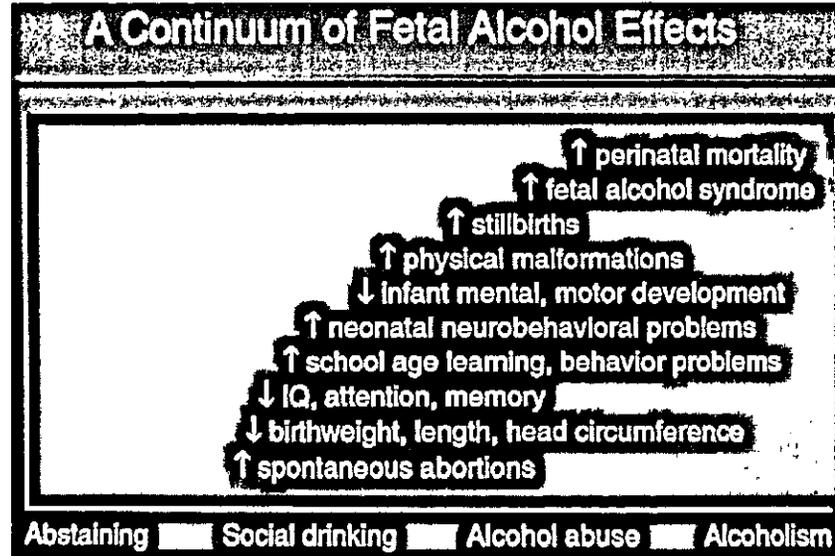


Exhibit 1.2: The Continuum of the Effects of Alcohol on Prenatal Growth and Development. The effects of alcohol on prenatal growth and development are a continuum (i.e., dose-related), with abstinence having no adverse effects. Alcohol abuse and alcoholism exert the most detrimental effects. Fetal Alcohol Syndrome is associated with chronic alcohol abuse (alcoholism) during pregnancy.

Alcohol has the potential to affect all organ systems during fetal growth and development, but the mechanisms by which alcohol induces its damage remain unknown. Many variables may be involved, including maternal nutrition, maternal metabolism, the pattern of alcohol consumption, the duration of exposure, the blood alcohol level of the mother, the timing of drinking during the pregnancy, concomitant drug exposure, and the genetic make-up of the fetus.

Human and animal studies have clearly demonstrated that alcohol is both a physical and a behavioral teratogen and that heavy prenatal alcohol exposure can lead to the distinct pattern of birth defects characteristic of the Fetal Alcohol Syndrome. (Jones *et al.*, 1973; Randall and Taylor, 1979; Randall and Riley, 1981) Although FAS is diagnosed in

children born to mothers who abuse alcohol chronically throughout pregnancy, children prenatally exposed *less* frequently to *less* alcohol may still suffer from neurobehavioral problems that are just as severe as those associated with the Fetal Alcohol Syndrome. (Mattson *et al.*, 1997; Mattson and Riley, 1999)

1.5.1 Primary Disabilities

Primary disabilities are related to the physical and Central Nervous System (CNS) abnormalities associated with FAS and FAE. Physical disabilities include skeletal deformities, muscle weakness, vision and auditory problems, and immune system deficiencies. CNS deficits include low IQ (Figure 1.2) and learning disabilities.

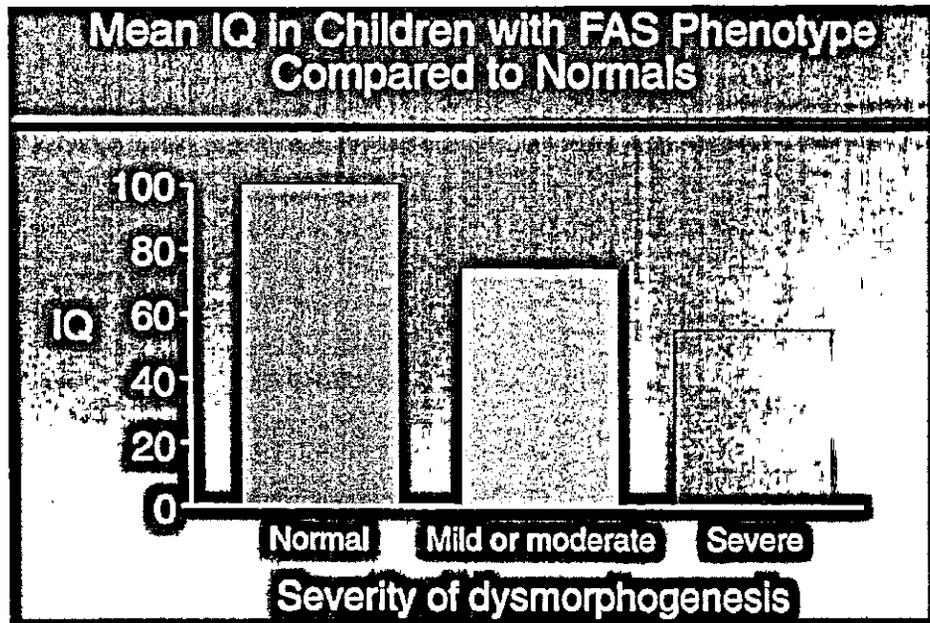


Figure 1.2: Mean IQ in Children with FAS. Studies among FAS patients yield IQ scores ranging from 65 to 70, reflecting intelligence levels in the bottom first or second percentile of the population. Clearly, there is a negative association between the severity of dysmorphogenesis and IQ.

Childhood deficits translate into significant problems when FAS and FAE individuals reach adulthood. (see Exhibit 1.3) They become easily victimized, angry, find it difficult to hold a job, and often end up in the criminal justice system.

FAS In Adolescents and Adults Clinical Implications	
Poor judgment	Easily victimized
Attention deficits	Unfocused / distractible
Arithmetic disability	Can't handle money
Memory problems	Doesn't learn from experience
Difficulty abstracting	Doesn't understand consequences
Disoriented in time and space	Fails to perceive social cues
Poor frustration tolerance	Quick to anger

Exhibit 1.3: FAS in Adolescents and Adults: Clinical Implications. Behavioral abnormalities in children have important implications in adolescence and in adulthood. Affected individuals often have difficulty functioning within the normal societal norms.

1.5.2 Secondary Disabilities

Secondary disabilities are defined as characteristics that develop over time where there is a chronic lack of a good fit between the needs of people with this disability and their environment. They are not intrinsic to the condition and, most importantly, are believed to be preventable or mitigated with appropriate supports.

Recent research at the University of Washington Fetal Alcohol and Drug Unit reveals an astonishingly high prevalence of secondary disabilities among a large group of over 400 patients with FAS and FAE. For those 12 years old and over diagnosed with FAS or FAE, the lifetime prevalence of mental health problems was over 90%; disrupted school experience was 60%, trouble with the law was also 60%; confinement in a residential treatment or correctional facility was 50%; inappropriate sexual behaviors was 50%; and alcohol and drug problems was 35%. Approximately 80% of those 21 years and over

had significant problems with employment and remained in some type of dependent living situation. (Streissguth *et al.*, 1997) Figure 1.3 illustrates the secondary disabilities associated with prenatal alcohol exposure.

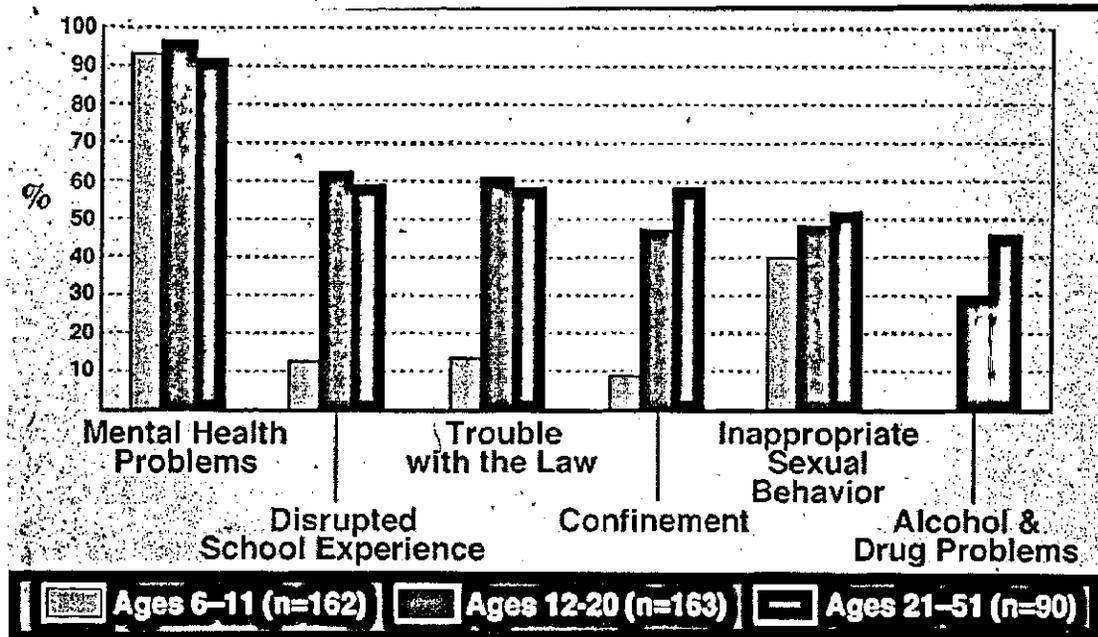


Figure 1.3: Secondary Disabilities Associated with Prenatal Alcohol Exposure. Prenatal alcohol exposure is associated with an increased risk for mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behavior, and substance abuse problems. Tendencies are dependent on age. These secondary disabilities can be mitigated and even prevented with proper intervention programs. (Streissguth *et al.*, 1997)

Table 1.1 summarizes the common characteristics of children with FAS/FAE.

Table 1.1: Common Characteristics of Children with FAS/FAE

Birth Defects	Small head, postnatal growth deficiency, identifiable facial features, major organ malformation, impaired vision, hearing loss, malformed ears.
Cognitive	mental retardation, speech and language disorders, mathematical deficiency, difficulty with abstraction, problems generalizing one situation to another, poor attention, poor concentration skills, memory deficits, impaired judgement and impaired comprehension and abstract reasoning.
Motor	motor delays, poor co-ordination, fine-motor impairment, clumsiness.
Behavioral	behavioral problems, infantile irritability, attention deficit disorder with hyperactivity; hyperactivity, impulsivity, lying, stealing, stubbornness, oppositional behavior.
Psychosocial	poor socialization or communication skills, failure to consider consequences of their actions, lack of reciprocal friendship, social withdrawal, sullenness, mood liability, teasing or bullying behavior, periods of high anxiety, excessive unhappiness, mental illness.
Secondary Disabilities	Mental health problems, chemical dependency, failure to develop appropriate sexual behavior, consequent legal problems, lying, stealing, impulsivity, lack of response to appropriate social cues, low self esteem, depression, school failure.

1.6 Implications of Primary and Secondary Disabilities Associated with Prenatal Alcohol Exposure

The implications of the primary and the secondary disabilities on the quality of life of individuals affected by prenatal alcohol exposure and those around them are significant. It is important to remember that, although the morphologic anomalies may be one of the cardinal features of Fetal Alcohol Syndrome, it is the Central Nervous System (CNS) dysfunction and the related secondary disabilities (see below) that interfere with the ability of affected individuals to function in society.

FAS/FAE patients tend to be impulsive, uninhibited, and fearless. They often display poor judgment and are easily distracted. Difficulties in perceiving social cues and a lack of sensitivity often cause interpersonal problems.

FAS individuals have difficulty linking events with their resulting consequences and this impacts their ability to learn from their mistakes. Lacking sufficient cognizance of the threat or fear of consequences, the FAS individual is less likely to control his or her impulsive behavior. Similarly, FAS individuals have trouble comprehending that their behavior can affect others and, as such, they are unlikely to show true remorse or to take responsibility for their actions. (Streissguth, 1997)

Ninety-five percent of FAS patients exhibit mental health problems. (Streissguth, 1997) They are prone to depression, panic disorders, hallucinations, and suicidal tendencies, all of which worsen with age.

Behavioral problems also increase with age. Among youth with FAS, 62% have severe behavioral problems and 50% exhibit inappropriate sexual behavior. This lends itself to victimization, unwanted pregnancies, and substance abuse. Unfortunately, the cycle of FAS/FAE is continued.

1.7 Diagnosis of FAS/FAE

Making a definitive diagnosis of FAS is complex and requires significant training and experience as well as access to a multi-disciplinary network (i.e., physician, psychologist, speech and language pathologist). Making the diagnosis depends on identifying a spectrum of clinical characteristics that are static and not due to post-natal factors.

1.7.1 Institute of Medicine Criteria

The Institute of medicine (IOM) criteria (Stratton *et al.*, 1996) are perhaps the most commonly utilized for making FAS diagnoses. Although they appear straightforward, they are not upon closer examination. For example, determining exactly which features (especially the neurobehavioral ones) are present and to what degree is often difficult and is subjective. The 1996 report sponsored by the Institute of Medicine (IOM) of the National Academy of Sciences classifies the effects of prenatal alcohol exposure into five categories outlined in Table 1.2.

Table 1.2: Institute of Medicine Diagnostic Criteria for Fetal Alcohol Syndrome

Diagnosis	Diagnostic Criteria		
	FAS Facial Features	Confirmed Prenatal Alcohol Exposure	Additional Criteria
FAS with confirmed maternal alcohol exposure	Yes	Yes	Growth retardation; central nervous system abnormality; or evidence of a behavioral or cognitive disorder inconsistent with the expected developmental level, with hereditary factors, or with the environment
FAS without confirmed maternal alcohol exposure	Yes	No	
Partial FAS with confirmed maternal alcohol exposure	Some	Yes	
Alcohol-Related Birth Defects	No	Yes	Any number of anomalies (such as heart or kidney defects) present at birth that are associated with maternal alcohol consumption during pregnancy
Alcohol-Related Neurodevelopmental Disorder	No	Yes	Evidence of central nervous system abnormalities (such as abnormally small head, abnormal brain structures, and neurological signs); evidence of a behavioral or cognitive disorder inconsistent with the expected developmental level, with hereditary factors, or with the environment, or both

Generally, the Institute of Medicine’s criteria consist of confirmed prenatal exposure to alcohol plus each of the following:

1. Craniofacial malformations
2. Pre- and post-natal growth deficits
3. Central Nervous System deficits (i.e., IQ, neurobehavioral dysfunction)

In order to receive a diagnosis of FAS, criteria including growth, facial malformations, and Central Nervous System deficits must be met. With the presence of some features, but not all, the diagnosis becomes Fetal Alcohol Effects (see below).

1.7.1.1 Growth

Children born affected by prenatal alcohol exposure have both pre- and post-natal growth deficits. They are small for gestational age while *in utero* and remain below average throughout their lifetimes with respect to head circumference, weight, and

height. Exhibit 1.4 illustrates growth curves for individuals diagnosed with FAS compared to normal, unexposed individuals.

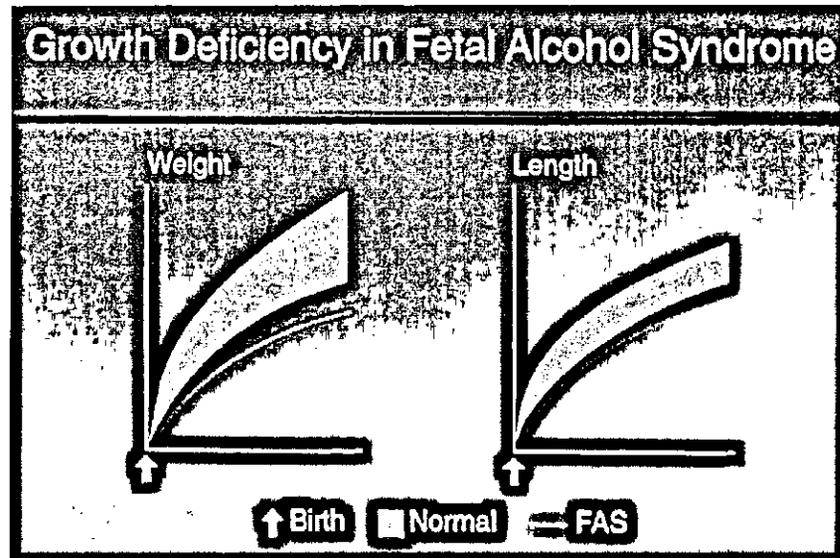


Exhibit 1.4: Growth Deficiencies Associated with Fetal Alcohol Syndrome. Children with FAS have both pre- and post-natal growth deficiencies. They remain below normal throughout their lifetimes with respect to weight and length (height).

Facial features are easier to distinguish in young Caucasian children (Exhibit 1.5) and can become less distinctive with age. Normative features among children of some ethno-cultural backgrounds (i.e., flat midface) also make confirmation of the presence of the facial features more difficult.

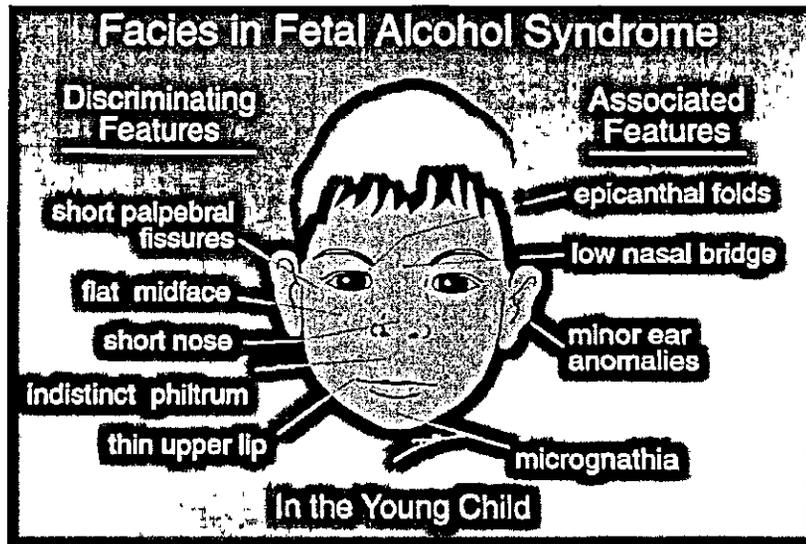


Exhibit 1.5: The Fetal Alcohol Syndrome Facies. The unique craniofacial profile of children with Fetal Alcohol Syndrome consists of eye, nose, ear, chin, ear, and lip abnormalities. These features can be less distinctive as the child ages and can be difficult to distinguish from some normal facial features of non-Caucasian races. Adapted from Streissguth *et al.*, 1994. (Streissguth *et al.*, 1994)

1.7.1.3 Neurobehavioral Deficits

Perhaps the most significant and most complicated deficits associated with prenatal exposure to alcohol are the neurobehavioral-related deficiencies. FAS-affected individuals tend to have low IQs, learning disabilities, and behavioral problems. (Mattson and Riley, 1998) The specific neurobehavioral manifestations of FAS are illustrated in Exhibit 1.6.

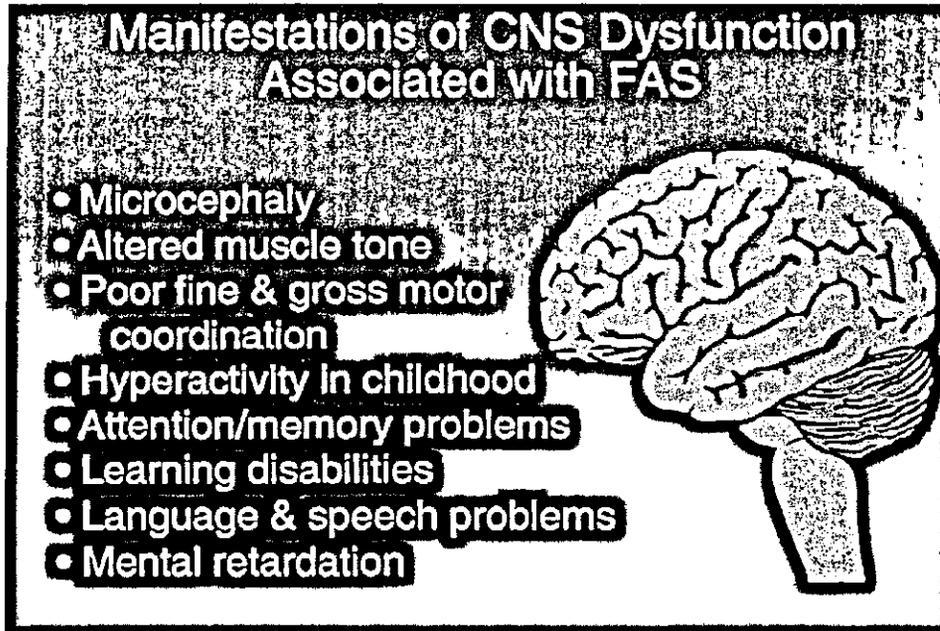


Exhibit 1.6: Neuro-Behavioral Deficits Associated with Fetal Alcohol Syndrome. Brain structure and function deficits as a result of prenatal alcohol exposure results in a number of Central Nervous System (CNS) dysfunctions that have clear implications for the quality of life of the individual.

Neurobehavioral deficiencies can be related to alcohol's detrimental effects on both brain anatomy and function. Children born with FAS tend to be microcephalic (i.e., they have small brains) to a degree that is not in proportion with their overall small body size. Data from animal models echo these findings, where brains of FAS rats (Maier *et al.*, 1997; Maier *et al.*, 1999) and mice (Cook *et al.*, 2001) are disproportionately smaller than their bodies. Exhibit 1.7 illustrates the effect of prenatal alcohol exposure on whole brain size and Exhibit 1.8 illustrates specific effects on the corpus callosum. Exhibit 1.9 shows the effect of prenatal alcohol exposure on three brain regions: the cerebrum, the corpus callosum, and the cerebellum.

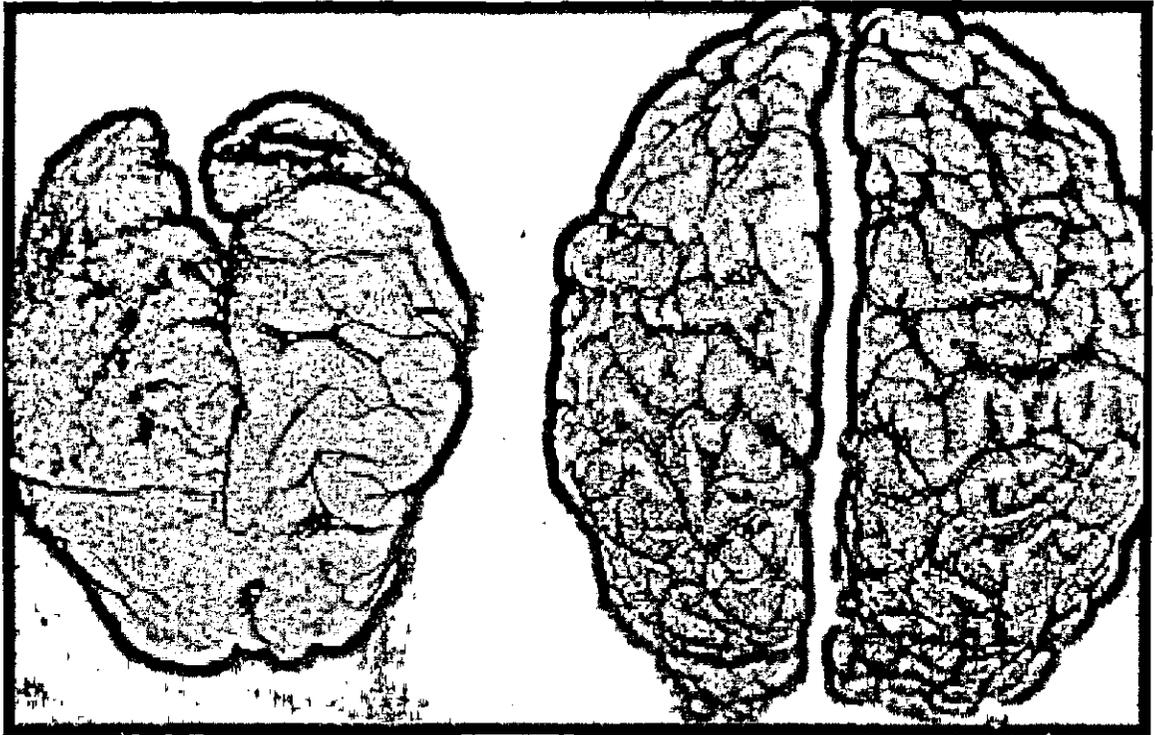


Exhibit 1.7: Effect of Prenatal Alcohol Exposure on Whole Brain Size. Prenatal alcohol exposure can have dramatic effects on whole brain size. The brain on the left is from a newborn diagnosed with FAS and that on the right is from an unaffected individual of the same age. (Photo courtesy of Sterling Clarren 1986) The brain from the FAS child is significantly smaller.



Exhibit 1.8: Effect of Prenatal Alcohol Exposure on the Corpus Callosum. This exhibit illustrates the range of the effect of prenatal alcohol exposure on the size of the corpus callosum (the white section the arrow refers to). All MRI scans are from individuals prenatally exposed to alcohol. The corpus callosum can be normal in size or may be absent. The average collosal size is reduced in individuals exposed to alcohol during fetal growth and development.

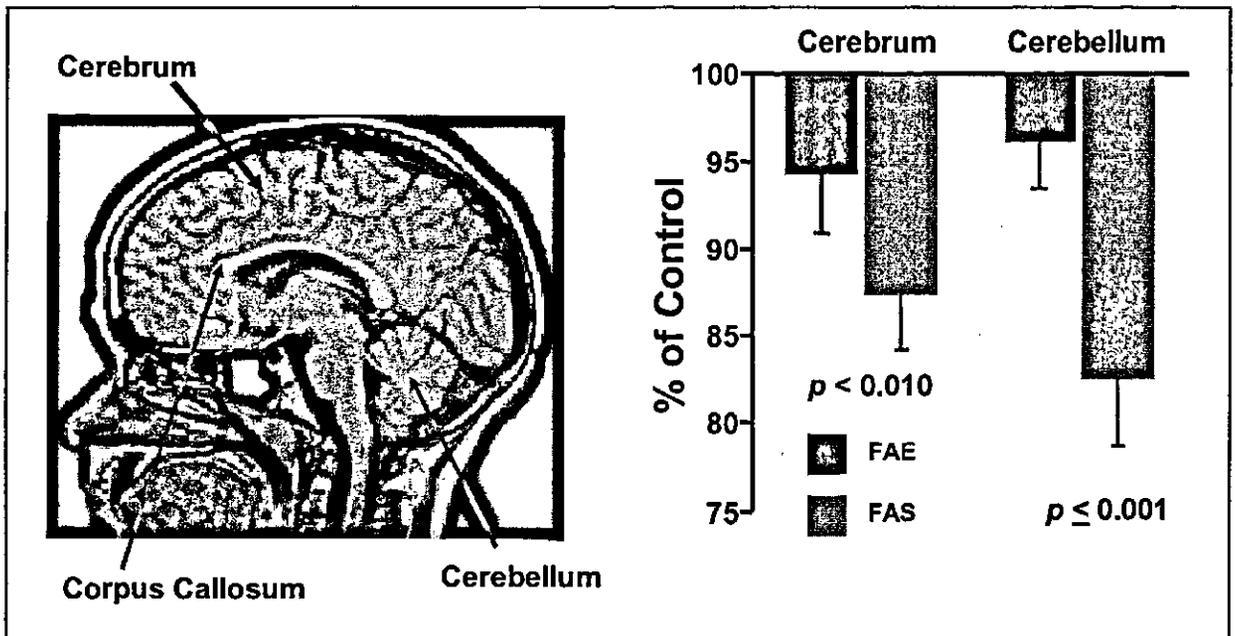


Exhibit 1.9: Effect of Prenatal Alcohol Exposure on Cerebral, Corpus Callosal, and Cerebellar Size. This exhibit illustrates the effect of prenatal alcohol exposure on the size of three brain areas; the cerebrum, the corpus callosum, and the cerebellum. The graph on the right illustrates that prenatal exposure to FAE and FAS are associated with smaller brain areas than control. FAS individuals have the most significant reduction in the brain areas evaluated. (Mattson *et al.*, 1994)

Although, in some cases, the brains of FAS-affected individuals may be normal in size, they are rarely normal in function. Alcohol is ubiquitous in its ability to affect all brain regions, but some regions appear to be more vulnerable than others (e.g., hypothalamus, corpus callosum, cerebrum, cerebellum). It is the damage in these regions of the brain that accounts for many of the associated and distinctive neurobehavioral of FAS/FAE.

1.7.2 Other Methods of Diagnosis

Although the IOM scheme includes categories for individuals with all or some of the FAS facial features and categories for alcohol-affected children without FAS facial features (“Alcohol-related birth defects” (ARBD) and “Alcohol-related neurodevelopmental disorder” (ARND)), it is important to point out that in many cases, ARBD and ARND are lumped together as FAE.

There are other diagnostic tools that have become available that may be used in conjunction with or instead of the IOM criteria.

1.7.2.1 The 4-Digit Diagnostic Code

The 4-digit diagnostic code is a comprehensive diagnostic system developed in 1997 to diagnose the full spectrum of outcomes among patients with prenatal alcohol exposure. It was developed to overcome the subjective, highly variable gestalt method for diagnosis that was frustrating physicians with the IOM criteria. The objectivity of the schema comes from the magnitude of expression of each feature being ranked independently on a 4-point Likert scale from absence of the feature to a strong presence. (Astley and Clarren, 2000) The 4-digit scale has been shown to correlate facial phenotype with brain structure and function. (Astley and Clarren, 2001)

The 4-digit diagnostic code breaks down an FAS diagnosis into 4 domains: Face, growth, brain, and exposure. The facial component quantitatively measures the magnitude of expression of the FAS facial features (palpebral fissure length, philtrum smoothness, and upper lip thinness). However, again, there are still elements of subjectivity, discrepancy, and confusion about rating the “brain” deficits, since these are measured by the neurobehavioral outcomes that are highly variable and differ from affected individual to affected individual. The 4-digit diagnostic code is simplified into Table 1.3.

Table 1.3: Four-Digit Diagnostic Code Criteria for Fetal Alcohol Syndrome

Score	FAS Facial Features	Growth Deficits	Brain Dysfunction	Gestational Alcohol
4	Significant	Severe	Definite	High Risk
3	Moderate	Moderate	Probable	Some Risk
2	Mild	Mild	Possible	Unknown
1	None	Absent	Unlikely	No Risk

1.7.2.2 ICD Criteria

ICD is the world-wide attempt to code diagnoses and procedures. It serves an important function for physician reimbursement, hospital payments, quality review, and measurements for benchmarking. The ICD code for newborns with FAS is 760.7 (see below).

The following is a description of the ICD code for Fetal Alcohol Syndrome:

760.7 Noxious influences affecting fetus via placenta or breast milk

- Fetus or newborn affected by noxious substance transmitted via placenta or breast milk
- Excludes: anesthetic and analgesic drugs administered during labor and delivery (763.5)
 - drug withdrawal syndrome in newborn (779.5)

760.70 Unspecified noxious substance

- Fetus or newborn affected by:

760.71 Alcohol

- Fetal alcohol syndrome

Clearly, the ICD procedure still allows significant room for subjectivity in making a diagnosis and may be more valuable as a recording tool after the diagnosis has been made.

1.8 Terminology

There has been much controversy over the use of terminology, in particular referring to FAE. Terms such as Alcohol-Related Birth Defects (ARBD), Alcohol-Related Neurodevelopmental Disorder (ARND), Partial FAS (pFAS), Prenatal Alcohol Effects (PAE), and Prenatal Alcohol Exposure (PAE) have been used to refer to FAE, but essentially they all have the same meaning. Most recently, Fetal Alcohol Spectrum Disorder (FASD) is being used to describe deficiencies and abnormalities associated with prenatal alcohol exposure. It is an umbrella term, however, and should not be used as a diagnostic term. A more specific diagnosis must be made (i.e., FAS) under the FASD umbrella to describe where in the spectrum the individual falls.

1.9 Prevalence of Maternal Drinking

Unfortunately, some pregnant women consume alcohol. Reviewing data from the Physician's Notice of Live Births between 1994 and 1996 in Alberta found that 7.5% of Alberta mothers admitted to drinking alcohol during pregnancy. (Alberta Health, 1997) Not surprisingly, however, the majority of these mothers reported only occasional or infrequent consumption and thus would not be anticipated to have children with clinical manifestations of prenatal alcohol exposure. Among natives surveyed in Northern Manitoba, however, over 50% of the women surveyed reported alcohol use during pregnancy. (Williams and Gloster, 1999) In New Zealand, Approximately a quarter of women continue to drink alcohol during pregnancy. (McLeod *et al.*, 2002) Thus, the occurrence of alcohol consumption during pregnancy varies widely among populations of pregnant women.

1.10 Prevalence of FAS and FAE

FAS is growing in significance worldwide and has surpassed Down's Syndrome and Spina Bifida to become the leading cause of mental retardation in North America. (Abel and Sokol, 1986; Warren and Bast, 1988) Fetal alcohol syndrome is prevalent around the world and across cultures, (Ferrier *et al.*, 1973; Beyers and Moosa, 1978; Clarren and Smith, 1978; Fitze *et al.*, 1978; Fried and Ravin, 1978; Miceli *et al.*, 1978; Okada,

1978; Scianaro *et al.*, 1978; Veghelyi *et al.*, 1978) yet prevalence rates are still largely estimates.

The estimated incidence of FAS in the United States is 1 to 3 cases per 1000 population (Sokol and Clarren, 1989) but the prevalence rates based on birth defect registry data are significantly lower. (1983: Institute of Alcohol, Alcoholism, and Alcoholics) The combined rate of FAS and FAE in Seattle has been recently estimated to be at least 9.1/1000, (Sampson *et al.*, 1994) thus, the prevalence of FAE is considered to be 8-10 times higher than that of FAS. Despite 20 years of recognition and billion of dollars invested into prevention and increasing awareness about the negative effects of prenatal alcohol exposure (See Exhibit 1.10 for samples), the incidences of FAS and FAE are reported to be increasing. (Sampson *et al.*, 1997)

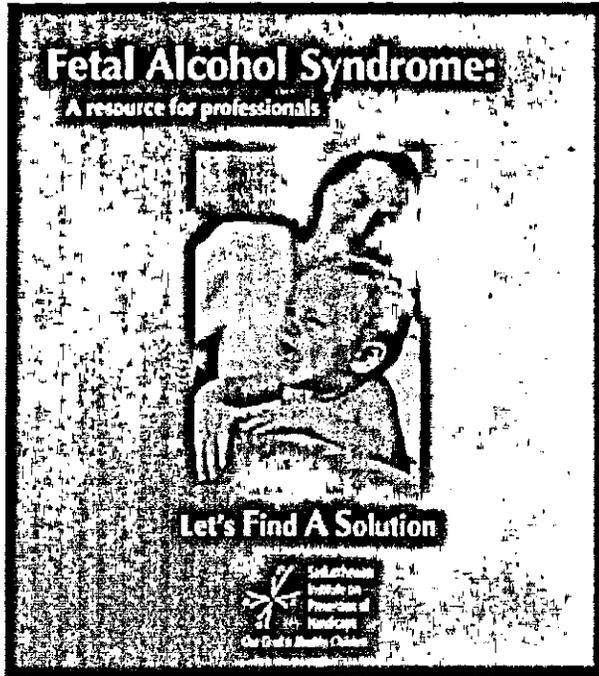


Exhibit 1.10: Samples of Posters and Pamphlets Aimed at Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects

1.10.1 Canadian Prevalence Rates of FAS/FAE

In terms of FAS and FAE prevalence, Canadian numbers are based upon estimated prevalence rates of industrialized countries for FAS of 1 - 3 per 1,000 births. It is estimated that in Canada at least one child is born with FAS each day. Unfortunately, there are no Canadian data that accurately describe incidence levels on a provincial or even National level. However, a few studies have reported high incidence rates in isolated Northern Canadian populations.

One study evaluated the incidence of FAS in northeastern Manitoba by examining all live births in one hospital over a one year period. It was reported there was an approximate incidence of 7.2/1,000. However, because only 46% of the high-risk cases were personally examined, incidence could be as high as 14.8/1,000. Surprisingly, only 1/5 FAS cases had been identified prior to this investigation, suggesting that the incidence of FAS in northeastern Manitoba is very high and that much greater effort needs to be made in its prevention and early detection. (Williams *et al.*, 1999) Why FAS wasn't being detected is unknown.

In Saskatchewan, 207 cases were ascertained, the majority from the Alvin Buckwold Child Development Program in Saskatoon. The rate of FAS was estimated at 0.589/1000 live births from 1988-1992 and was reported as 0.515/1000 in 1973-1977. (Habbick *et al.*, 1996) It is not known why these estimates are so much lower than those of the United States.

Another study was designed, at the invitation of a band council (The Canim Lake Band), to determine the prevalence of prenatal alcohol exposure among children in a native Indian community in British Columbia. The mothers of the 123 children aged 18 years or less who lived in the community were interviewed. A diagnosis of FAS or FAE was made in 22 children aged 3 to 18 years, (Robinson *et al.*, 1987) suggesting a combined prevalence rate of 17.9%. These studies also suggest variation in the prevalence of FAS and FAE in different communities across Canada and lend support to the need for further understanding of the demographic implications.

1.11 Demographics

There are indications that there is a demographic component to the prevalence of FAS and FAE. Data suggest that the prevalence rates for FAS and FAE are significantly higher in rural residents (May *et al.*, 2000), among natives and American Indians (Burd and Moffatt, 1994; Egeland *et al.*, 1998), and Aboriginal people of Canada. (Bray and Anderson, 1989; Burd and Moffatt, 1994; Loney *et al.*, 1998)

Table 1.4 illustrates the results from a survey of the literature where prevalence rates have been estimated worldwide.

Table 1.4: Prevalence Estimates of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)

Location	FAS Prevalence (/1000 live births)	FAE Prevalence (/1000 live births)	Reference
Alaska	0.2 (non-AI/AN) 3 (AI/AN)		(Egeland <i>et al.</i> , 1998)
Aberdeen	3.9 (AI/AN)		(Duimstra <i>et al.</i> , 1993)
Institute of Medicine Report	0.6-3 (non-AI/AN) 2-8.5 (AI/AN)		(Stratton <i>et al.</i> , 1996)
Seattle	2.8	9.1 (FAS and FAE)	(Sampson <i>et al.</i> , 1997)
Cleveland	4.6		(Sampson <i>et al.</i> , 1997)
Roubaix	1.3-4.8		(Sampson <i>et al.</i> , 1997)
South Africa (Wellington)	48		(May <i>et al.</i> , 2000)
South Africa (Western Cape)			(Viljoen, 2003)
	1997	46.4	
	1999	74.7	
	2002	100.2	
South Africa (Gauteng, 4 areas)			(Viljoen, 2003)
	2000	0-37	
South Africa (Northern Cape, 2 areas)			(Viljoen, 2003)
	2001-2002	53-103	

** AI means American Indian; AN means American Native

Clearly, the studies performed in South Africa illustrate extremely high prevalence rates for FAS. These were communities who reported high rates of alcohol consumption and

are considered high risk populations for Fetal Alcohol Syndrome – rates cannot be generalized for the population at large.

In Alaska, it was reported that the prevalence of FAS among American Indians/American Natives was 15 times more than the prevalence among non-American Indians/American Natives. (Egeland *et al.*, 1998) The Institute of Medicine also reported a higher incidence among American Indians/American Natives. (Stratton *et al.*, 1996) Together, with Table 2, these data suggest the presence of either ethnic or demographical implications for the prevalence of FAS and FAE.

It should be emphasized that, despite the possibility of an ethnic effect on FAS and FAE prevalence, disabilities related to prenatal alcohol exposure are not associated with races (a common misconception) but are, indeed, associated with socio-economic status. Abel (Abel, 1995) examines data from U.S. and European studies and concludes that the major factor associated with FAS is low socio-economic status rather than racial background. One study reports a highly significant difference in the incidence of FAS offspring between upper, middle, and lower class alcoholic mothers. (Bingol *et al.*, 1987) There was a 4.5% likelihood of having an FAS offspring among the upper middle class and 70.9% in the lower class. Outcomes such as congenital malformations, failure to thrive, and mental retardation were also significantly greater in children of lower class alcoholic women. (Bingol *et al.*, 1987) These differences could be related to such variables as access to pre- and post-natal care and services, inadequate nutrition, and a poor developmental environment.

Other investigators invited all women reporting alcohol consumption at conception of at least 0.5 oz absolute alcohol/day and a 5% random sample of lower level drinkers and abstainers to participate in a study to be able to identify the associations between alcohol intake and child development. Maternal alcohol, cigarette, and illicit drug use were prospectively assessed during pregnancy and postnatally. (Sood *et al.*, 2001) The data suggest that risk factors for prenatal alcohol exposure included higher maternal age and lower education level, prenatal exposure to cocaine and smoking, custody changes,

lower socioeconomic status, and paternal drinking and drug use at the time of pregnancy. (Sood *et al.*, 2001)

In the United States, there is reported to be a higher prevalence of FAS among African Americans (Abel, 1995) as well as Native Americans (Stratton *et al.*, 1996; Egeland *et al.*, 1998), both groups that tend to be of lower socio-economic status in the United States. (Abel, 1995; May and Gossage, 2001)

Obviously, it would be of interest to investigate the demographic and geographic profiles of FAS and FAE. Better understanding of the association between demographics, geography and prevalence rates could lead to more appropriate (i.e., community and culture-specific) prevention and intervention programs for affected communities.

1.11.1 Intervention Programs

Intervention refers to activities intended to prevent and reduce harmful effects associated with primary and secondary disabilities among persons exposed to alcohol *in utero*.

Intervention aims to promote the optimal development of individuals exposed to alcohol or other substances prenatally, during the various life stages and to support those caring for them. Due to the range of disabilities associated with FAS/FAE, intervention may involve parenting classes, family support, and programs designed to overcome educational, mental health, vocational, young offender, and criminal justice issues. Thinking about the role of the brain in dysfunction associated with prenatal alcohol exposure is central for the development of appropriate and effective intervention programs.

A great deal of neurological development occurs after birth and early interventions can significantly improve the outcome of FAS/FAE children, particularly in cases where the defects are less severe. Expert researchers in the field (Streissguth *et al.*, 1997;

Streissguth, 1997; Streissguth and Kanter, 1997; Astley and Clarren, 1999) have called for early diagnosis and prompt intervention with families of alcohol-affected children to promote the development of these children and to minimize the occurrence of secondary disabilities. More specifically, data suggest that multifaceted intervention programs throughout the lifetime of the individuals affected by prenatal alcohol exposure are crucial to improve their outcome and, as such, will significantly reduce secondary disabilities that have implications for justice, health, education, and social services. With this reduction in secondary disabilities and by fostering affected individuals to reach their potential and to become productive members of society, a significant positive economic impact will be evident to society.

1.11.2 Importance of FAS and FAE Diagnosis

In order for affected individuals to receive the care, support, and access to the types of programs and facilities that will improve outcome, a diagnosis is often required. The importance of early intervention programs has already been emphasized, but access to specialized intervention programs is dependent upon the child receiving a diagnosis of FAS or FAE. Diagnosis, however, is a complicated matter and surveys suggest that physicians do not feel comfortable with diagnosing FAS and FAE. (Nanson *et al*, 1995; see Chapter 4) The neurobehavioral effects are complex, but diagnosis of the physical/morphological characteristics associated with FAS/FAE should be synonymous with recognition of Central Nervous System effects and associated behaviors.

Diagnosis also provides a signal for identification of subtle deficiencies. Many times children can appear successful on hearing or vision tests, yet their level of comprehension is low. Slow cognitive pace, thinking more slowly, hearing more slowly, or usual screens may be missed or be under- or oversensitive to the surroundings. Identification supports further exploration about subtle differences which may have a significant impact on the child's quality of life and experience within his world.

When linked to support programs, diagnosis may directly prevent the development of secondary disabilities and symptoms. (Streissguth, 1997) When linked with understanding of the idiosyncrasies and characteristics of the deficits associated with FAS and FAE, it can prevent deterioration of the condition and can, instead, promote productive development. Finally, when linked to successful outcomes, diagnosis contributes to preventing a future generation affected with FAS, FAE, and their related disabilities. Clearly, diagnosis *because of* its linkage to appropriate services, is key to improving for all individuals, families, and communities affected by FAS and FAE.

1.11.3 Diagnosis Programs in Saskatchewan

Prevention and intervention programs geared toward FAS and FAE have been provided in Saskatchewan for a number of years. The Saskatchewan Institute on Prevention of Handicaps offers FAS education and prevention programs. The Alvin Buckwold Child Development Program at The Kinsmen Children's Centre supports a diagnostic clinic as well as intervention programs consisting of physical and occupational therapy and counseling, in an attempt to reduce secondary disabilities associated with prenatal alcohol exposure. Provincial governments also offer limited financial support for programs geared to improve the outcome of individuals, families, and communities affected by FAS and FAE. However, the success of these programs is unknown and funding agencies tend to be unaware of the cost:benefit of providing funding. By increasing capacity and effectiveness of intervention programs, the large economic tolls that FAS and FAE take on society would be significantly reduced since the subsequent development of secondary disabilities would be mitigated. As a result, society, overall, would benefit economically as well as non-economically.

2.0 Study 1: Some Economic Costs of FAS and FAE in Saskatchewan

2.1 Introduction

Fetal Alcohol Syndrome and its related secondary disabilities exert a significant impact on Canada's economy. Individuals affected by prenatal exposure to alcohol often require specialized education, care and facilities throughout their lifetime. In addition, the many secondary disabilities that arise, not as a direct result of the condition itself, but rather as a lack of fit between affected persons and the society in which they live, impact their ability to live independently, function according to societal norms, and remain gainfully employed.

There are very little data available with respect to the economic costs associated with of FAS and FAE in Canada. It has been suggested that caring for people now living with FAS and FAE will cost at least \$600 billion. (McLean and Candis, 2000) Although it wasn't specified, this number is presumably comprised of costs associated with the use of all services and programs by affected individuals and their families as well as some intangible costs (i.e., loss of potential income and decreased quality of life).

Saskatchewan is presumed to have a high prevalence of FAS and FAE, partly due to its large rural Northern population. A recent study suggests that, in Saskatchewan, the highest incidence of FAS occurs in the in the Aboriginal population. (Loney *et al.*, 1998) While the birth rate of the non-Aboriginal population in Saskatchewan remains constant, the Aboriginal population is growing at a rate of 1.7% per year. Thus, by 2011, the Aboriginal peoples will make up 38% of Saskatchewan's total population. (Smith, 1997) With the increasing birth rate of vulnerable populations coupled with the cyclicity of FAS/FAE (because of the increased risk for early sexual relations,

unprotected sex, and substance abuse) comes a synergistic effect with respect to the number of future children with FAS and FAE. With this prevalence comes the potential high economic costs associated FAS/FAE. The costs associated with FAS and FAE in Saskatchewan are hypothesized to be significant.

2.1.1 FAS/FAE and the Criminal Justice System

Clearly, the primary and secondary disabilities associated with FAS and FAE affect the quality of life of affected individuals as well as the quality of life of those who provide care for them. Neurobehavioral deficits make FAS and FAE affected individuals more susceptible to crime and criminal behavior and consequently has implications for the justice system. Surprisingly, however, there are not accurate estimates of the number of affected individuals appearing before the courts, nor are there data with respect to the number of individuals in correctional facilities who are affected by prenatal alcohol exposure.

Fast *et al.* (Fast *et al.*, 1999) recently reported that 1% of youth remanded for a forensic psychiatric/psychological assessment were diagnosed with FAS and 23.2% had a diagnosis of FAE in a British Columbia study. Saskatchewan statistics are anticipated to be similar and costs associated with the disproportionately high numbers of individuals with FAS/FAE in the Saskatchewan justice system are expected to be very high.

In Saskatchewan, there have been no systematic studies documenting the prevalence of individuals who have experienced prenatal exposure to alcohol. A Saskatoon judge has reported observing high numbers of affected individuals before her bench. (Turpel Lafond, 2002b) There are currently plans underway to design and to develop a screening/identification tool for FAS and FAE to be used in the youth offender system. (Prediger, 2002) This is of significance because, although FAS and FAE diagnosed individuals appear to fare well in the structured environment associated with incarceration (Zakreski, 1998), since they neither learn from experience nor understand the concept of consequence, there is much controversy as to whether incarceration or is

the most appropriate consequence for these individuals. Determining the prevalence of FAS/FAE in Saskatchewan's justice facilities as well as being able to gather data on the repeated offences and sentences of affected individuals will allow for cost estimates associated with justice. These estimates should direct policy development around appropriate forms of punishment for individuals affected by prenatal alcohol exposure.

2.1.2 FAS/FAE and the Education System

Neurobehavioral problems associated with prenatal alcohol exposure are also underlying the need for special education programs for affected individuals. FAS and FAE children tend to be in special education classrooms and require additional time and attention from teachers and teachers' aides. They tend to be disruptive in the classroom, taking time away from the studies of other children. Also, special education programs designed for children with other disabilities may not be the most appropriate for those prenatally exposed to alcohol if the teacher does not understand the associated profile of neurobehavioral abnormalities and the most current evidence-based best practices.

In Saskatchewan, costs associated with special education are significant and funding for programs in the public school system come from provincially provided grants for each child; \$8,000/year for a Level I special education program and \$12,000/year for Level II. Unfortunately, Saskatchewan Education does not have the number of children with confirmed FAS or FAE diagnoses in their records.

2.1.3 FAS/FAE and Health Systems and Services

Individuals exposed prenatally to alcohol have many more health complications than the general population, being vulnerable to decreased immune function, cardiac problems, vision and hearing problems, musculoskeletal defects, increased risk for cancers, and significant mental health problems. Hence their utilization of health systems and services (especially with respect to mental health) is significantly greater than utilization by unaffected individuals. A recent Saskatoon study by Loney *et al.* (Loney *et al.*, 1998) reports that FAS-diagnosed children have higher hospital utilization rates than

non-affected children. Thus, costs associated with increased ailments and increased utilization of health systems and services (especially mental health services) are anticipated to be high for FAS/FAE individuals.

2.1.4 FAS/FAE and Social Services

The cost of FAS and FAE to the social services budget is probably significant. Affected individuals and their families would be expected to have higher utilization of social services, although there are no data available on the subject. Social workers are often assigned to the child and to their family. Adoptive and foster care services are highly utilized, since it is well-known that a large proportion of FAS children are adopted or live in foster care. (Caruso and ten Bensel, 1993) Repeated attendance at family counseling and parenting classes are also often characteristic of FAS and FAE-affected individuals and their families.

Individuals are not labeled as being diagnosed with FAS or FAE within Saskatchewan's Social Services registry.

2.1.5 Other Costs

There are additional economic costs, some tangible and some intangible, associated with Fetal Alcohol Syndrome. Most obvious are costs associated with alcoholism, since at least one parent of FAS-affected individuals is a problem drinker (the mother) and FAS/FAE individuals are at more risk to be alcohol (and drug) abusers themselves. Thus, there are direct and indirect costs associated with substance abuse.

In the United States, the total losses to the economy related to alcohol and drug abuse and mental illness for 1988 were estimated to be \$273.3 billion. The estimate included \$85.8 billion for alcohol abuse, \$58.3 billion for drug abuse, and \$129.3 billion for mental illness. These total costs also include costs associated with direct treatment and support, morbidity, the value of reduced or lost productivity, mortality costs, the value of foregone future productivity for the 140,593 premature deaths associated with these

Disorders ... \$47.5
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disorders, and \$47.5 billion in other related costs, including the costs of crime, motor vehicle crashes, fire destruction, and the value of productivity losses for victims of crime, incarceration, crime careers, and caregiver services. (Rice *et al.*, 1991)

FAS-affected individuals, because of their high victimization rates, increased risk for substance abuse, and lack of understanding of consequences, would also be at increased risk for sexually transmitted diseases, including HIV and herpes. Again, in the United States, the cost of AIDS associated with drug abuse is estimated at \$1 billion. Estimated for all costs, although not available in Canada, would be similar.

Other less-measurable tangible costs can also be attributed to FAS and to FAE, including the inability of affected individuals to remain gainfully employed, time taken by increased need for parental and teacher attention, and requirements for dependent living. For example, most individuals with FAS have a lower IQ than non-affected individuals, but sometimes with borderline scores that will not qualify them for services for the disabled. (Loock, 2002) However, only 10 percent of affected individuals can achieve independence and most adults with FAS require long-term support with close supervision for the rest of their life. Costs of residential care range from \$2,000 per month for a group home to \$4,500 per month for prison to \$24,000 per month for psychiatric hospital care. Studies show that 60% of individuals with FAS/FAE end up in a mental health facility or prison. (Streissguth, 1996) In Saskatchewan, this translates into additional costs of over \$66.5 million, based upon the number of affected individuals in the prison population, based on Fast's (Fast *et al.*, 1999) data (using an average cost of \$2500/month).

2.2 Study Objectives

Although many predictions and estimates have been made as to the economic costs of FAS and FAE to society, specific cost data has not been obtained for Saskatchewan. Saskatchewan's prevalence of FAS and FAE could well-exceed that used as the standard National average because of the growing demographic population of affected

individuals. Therefore, costs associated with FAS and FAE to Saskatchewan's economy are anticipated to be large and also are anticipated to increase over time. The most significant measurable tangible costs are expected to be in relation to services provided in the justice, social services, education, and health systems. Thus, this study was designed to determine some economic costs of FAS and FAE in these four sectors of society in Saskatchewan. Determining some of the economic costs of FAS and FAE to Saskatchewan will allow the best use of funds to develop and to implement programs that have the largest impact on mitigating the long-run costs of prenatal alcohol exposure.

2.3 Methods

Attempts were initially made to determine utilization of health, justice, and social services by FAS and FAE individuals by searching the Provincial databases from Saskatchewan Health, Saskatchewan Justice, and from Saskatchewan Social Services. Databases were to be searched electronically with respect to services utilized by FAS and FAE-affected individuals and their families as well as for the extent of their utilization. Costs were based upon published costs for the services by each sector.

However, it was discovered that individuals affected with FAS/FAE are not labeled as such in the databases, either due to unconfirmed diagnoses or unwillingness to "label" the individual. Therefore, this methodology for data collection was, unfortunately, not possible. Because it would still be helpful to estimate the economic costs of FAS/FAE to Saskatchewan to help direct effective use of provincial funds for services, as an alternative methodology, data were estimated for social services, health services, and for justice based upon provincial budgets allocated to these departments and published National prevalence rates of FAS and FAE (see Appendices I-V for calculations). Data were obtained with respect to education costs for FAS and FAE based upon the Saskatoon School District's Principal's Report for 2001, which offered information with respect to costs of special education services and numbers of children enrolled in such programs throughout Saskatchewan. Again, Saskatchewan Education's database does

not label children with FAE or FAE so National prevalence rates had to, again, be utilized to gather data.

A case method was also utilized to estimate the typical cost of an FAS child from birth to adulthood. Services and the extent to which they would be utilized were estimated based upon the case analysis of a 13 year old First Nations boy with FAS. Data were provided by his birth mother. (Cutknife, 2002) Costs were applied to each service using information obtained in the literature and from the appropriate agencies of the Saskatchewan government for services utilized. Costs were estimated based upon the lifetime of the FAS affected individual and projections of services utilized. All medical procedural costs were based upon the schedule of benefits for physician services. Based on National prevalence data, these estimates were used to extrapolate the lifetime tangible costs associated with FAS. It must be emphasized that these data are merely representative of the costs associated with FAS and are based upon a single case study. No other case study data were available in sufficient detail for analysis.

2.4 Results

2.4.1 Justice

Prevalence rates of FAS (1%) and FAE (23.3%) in the Youth Offender system were used based on reported rates in a British Columbia study of Youth Offenders. (Fast *et al.*, 1999) This is the only study with rates that have been quantitated for the justice system, so these estimates have been used as the basis for the cost data in this study. Saskatchewan Justice reports that incarceration of each individual costs \$100,000 per year for the Youth Offender system. (Prediger, 2002) The total number of cases processed in Saskatchewan youth courts was 9,062 in 1999-2000, and 66% of these cases (5,981) resulted in conviction. On average, about 2,900 youth are involved, at any point, in the young offenders system (Government of Saskatchewan, 2002), and approximately 442 are in custody at an average cost of \$85/day/youth. (Statistics Canada, 2002) One percent of these (or 4 youth) could be expected to have FAS and 22.3% (or 99 youth) could be expected to have FAE, according to Fast's estimates. (Fast

et al., 1999) Thus, costs of FAS and FAE to Saskatchewan Justice for youth custody are extrapolated to be \$137,130/year and \$3,058,010/year, respectively, with a total cost of \$3,195,140 attributed to prenatal alcohol exposure (Table 2.1: For calculations, please refer to Appendix I).

Table 2.1: Estimated Cost to the Saskatchewan Youth Offender System (2000) of Having FAS and FAE Individuals in Custody

	Number of individuals in custody	Estimated Cost (per year)
FAS	4	\$137,130
FAE	99	\$3,058,010
Total	103	\$3,195,140

It is important to point out that these costs only include costs associated with *youth* custody, and do not include the expenditures associated with adult corrections. We know that, because of their inability to learn from experience and to understand consequences, individuals affected by prenatal alcohol exposure are not rehabilitated as a result of youth incarceration and end up, eventually, in the adult justice system. For the purposes of this study, we are assuming that the prevalence rates of prenatal alcohol exposure in the adult system are the same as those reported for the youth system. (Fast *et al.*, 1999) Based upon data from Statistics Canada (Statistics Canada, 2002), suggesting that costs of adult corrections are 4.5 times more than youth corrections, the costs of FAS and FAE to the adult corrections system can be estimated as \$14.4 million (Figure 2.1: For calculations, please refer to Appendix II).

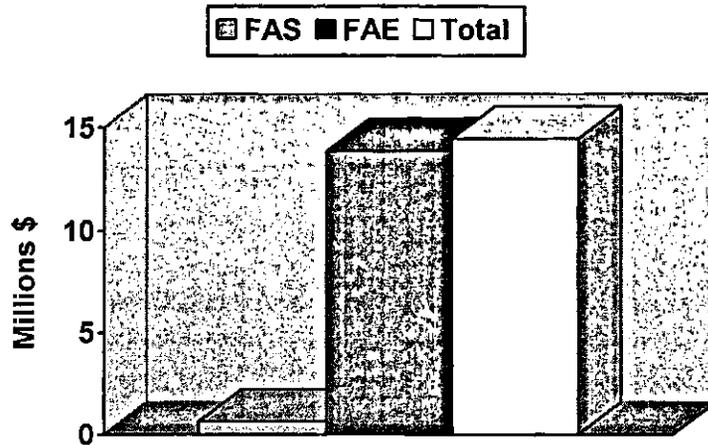


Figure 2.1: Estimated Costs Associated with FAS/FAE Individuals in Custody to Adult Corrections in Saskatchewan (2000). Costs of FAS to adult corrections in Saskatchewan are estimated to be \$617,087/year and costs of FAE \$13.8 million/year. The total cost of prenatal alcohol exposure to Adult Corrections in Saskatchewan is estimated as \$14.4 million.

Thus, the total costs of prenatal alcohol exposure to the Saskatchewan Justice system (youth and adult corrections) were extrapolated to be \$17.6 million (Figure 2.2) for 2000 (For calculations, please refer to Appendix II). These costs may be underestimated, given that individuals affected by prenatal alcohol exposure tend to be repeat offenders. (Turpel Lafond, 2002) However, in order to make accurate references with respect to the marginal cost of having FAS/FAE, rates of utilization of justice systems and services by affected individuals must be determined. These estimates are clearly per capita estimates.

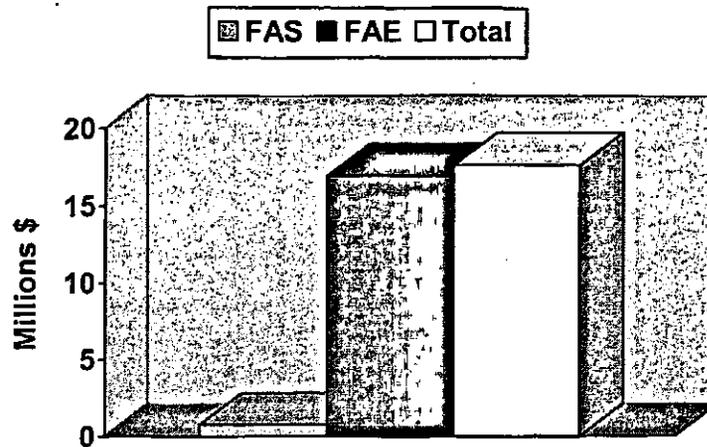


Figure 2.2: Estimates of Custody-Associated Costs of FAS/FAE to Saskatchewan (2000). Costs of FAS to Saskatchewan Justice (youth and adult corrections) are estimated to be \$754,217/year and costs of FAE \$16.8 million/year. The total cost of prenatal alcohol exposure to Saskatchewan Justice can be estimated as \$17.6 million.

2.4.2 Social Services

The budget from Saskatchewan Social Services was reported as \$588 million for 2000-2001 (Saskatchewan Social Services, 2000-2001) and, according to the estimated FAS prevalence rate of 0.2% in the population, \$1.2 million of this budget will be spent caring for individuals diagnosed with FAS. An additional \$4.7 million will be spent on individuals diagnosed with FAE (assuming a 0.8% prevalence rate). (Figure 2.3: For calculations, please refer to Appendix III) These costs are grossly underestimated, however, because they do not include increased utilization of services by FAS/FAE individuals and their families. It must be noted that, because population estimates are being used, the marginal cost associated with prenatal alcohol exposure is not determined. For example, 10% of the population is estimated to have FAS or FAE, so 10% of the total budget is attributed to FAS/FAE. However, others in the population still access social services even though they do not have FAS/FAE. In fact, they may have FAS/FAE with another medical condition (a co-morbidity). Without utilization data for individuals diagnosed with FAS/FAE, marginal costs cannot be determined.

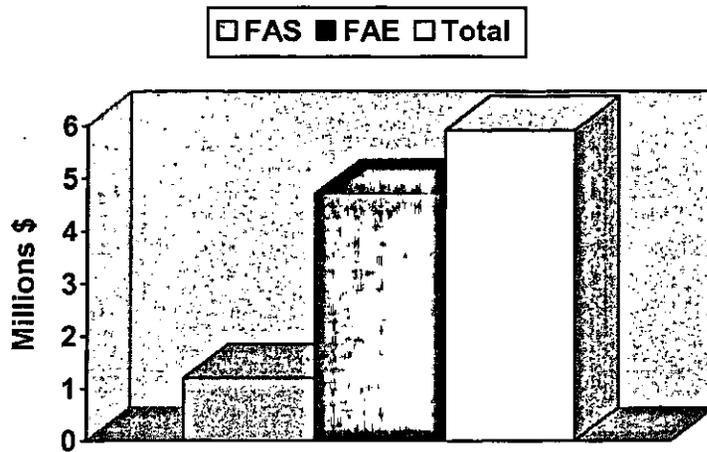


Figure 2.3: Estimated Costs of FAS and FAE to Saskatchewan Social Services. Costs of FAS to Saskatchewan Social Services are estimated to be \$1.2 million/year and costs of FAE \$4.7 million/year. The total cost of prenatal alcohol exposure to Saskatchewan Social Services can be estimated as \$5.9 million.

2.4.3 Education

The numbers of children affected by prenatal alcohol exposure in the school system remain unknown. The Saskatoon school board estimates that there are currently 22,143 children enrolled in their system (2001-2002), with only 1 (0.005%) recorded as having FAS and 29 (0.13%) enrolled with FAE in their system. (Forrester, 2002) The underestimation is evident based on population estimates of 44 children with FAS (0.2% of 22,143) and 177 with FAE (0.8% of 22,143).

Based upon the Saskatchewan Principal's Report (Saskatchewan Education, 2000-2001), costs for Special Education programs in Saskatchewan can be calculated at \$2.45 million/year. FAS is associated with \$48,960 of these costs and FAE with \$195,840 (Figure 2.4: For calculations, please refer to Appendix IV), according to assumed prevalence rates of 0.2% and 0.8%, respectively. Thus, the total cost of prenatal alcohol exposure is estimated to be \$244,800. These costs only consider those associated with Special Education and do not include monies for teacher's assistants and other special arrangements.

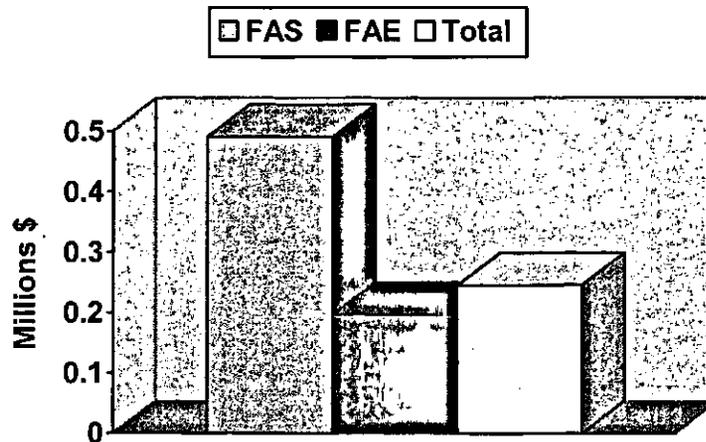


Figure 2.4: Estimated Costs of FAS and FAE to Saskatchewan Education. Costs of FAS to Saskatchewan Education are estimated to be \$48,960/year and costs of FAE \$195,840/year. The total cost of prenatal alcohol exposure to Saskatchewan Education can be estimated as \$244.800.

Having the capacity to offer special education programs to all children in need, however, would mean significant expenditures by Saskatchewan Education. For example, if there are estimated to be 44 (FAS) plus 177 (FAE) affected children in the Saskatchewan school board's jurisdiction and, at present, only 30 are receiving specialized education services, an additional \$1.7 million/year would be needed, based upon an average cost of \$9000/child/year for special education programs, for the 191 individuals in need. It is assumed, based on the literature, (e.g., Streissguth *et al.*, 1997) that all affected individuals would require some sort of special education.

2.4.4 Health Care Costs

Although we know that individuals with FAS have increased hospitalization rates (Loney *et al.*, 1998), we do not know the specificities of the overall increase in health services utilization. Because of this, costs of FAS and FAE to the Saskatchewan health care system must be extrapolated based upon prevalence data and the budget of Saskatchewan Health. Again, the ability to calculate and to determine marginal cost, as well as to determine the prevalence of co-morbidities, would be a stronger approach to estimating health care costs associated with FAS/FAE.

Saskatchewan Health's annual budget for 2000-2001 was reported as \$2.03 billion. (Saskatchewan-Health, 2000-2001) Using estimated prevalence rates of 0.2% for FAS and 0.8% for FAE, costs of FAS can be calculated to be \$4.1 million for 2001 and costs for FAE, \$16.2 million. Again, because of the population-based methodology and the inability to access service utilization information by affected individuals, marginal costs of prenatal alcohol exposure to Saskatchewan's health system cannot be determined. Data are outlined in Figure 2.5. For calculations, please refer to Appendix V.

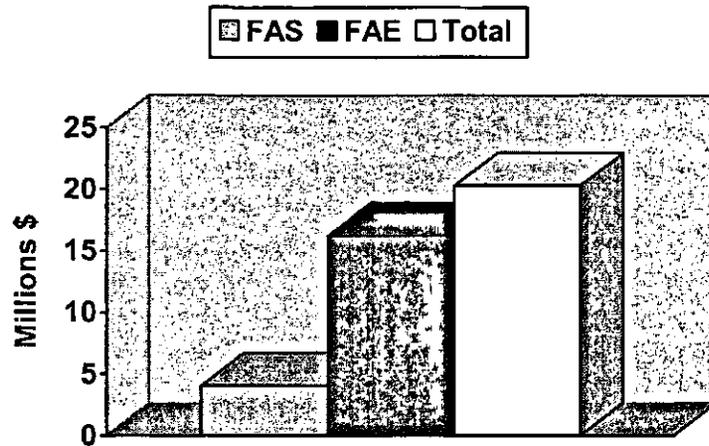


Figure 2.5: Estimated Costs of FAS and FAE to Saskatchewan Health. Costs of FAS to Saskatchewan Health are estimated to be \$4.1 million/year and costs of FAE \$16.2 million/year. The total cost of prenatal alcohol exposure to Saskatchewan Health can be estimated as \$20.3 million/year.

In total, the dollar figure that FAS and FAE cost Saskatchewan with respect to Justice, Social Services, Education, and Health Services is estimated to be \$44 million per year (Figure 2.6: For calculations, please refer to Appendix VI).

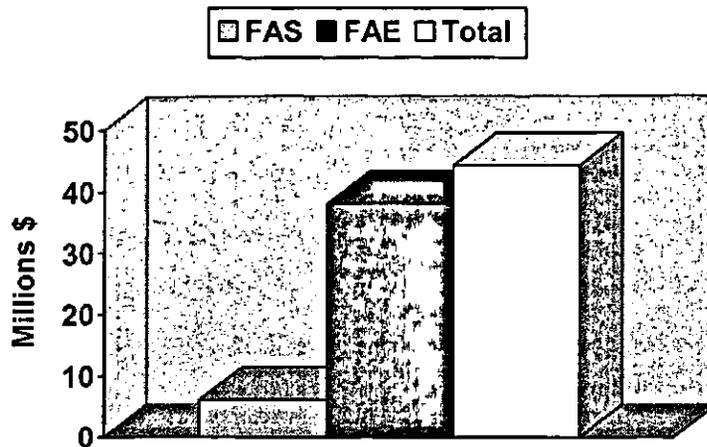


Figure 2.6: Estimated Costs of FAS and FAE to Saskatchewan. Costs of FAS to Saskatchewan Justice, Health, Education, and Social Services are estimated to be \$6 million/year and costs of FAE \$37.8 million/year. The total cost of prenatal alcohol exposure to Saskatchewan Justice, Health, Education, and Social Services can be estimated as \$44 million/year.

2.4.5 Case-Based Analysis

Two short cases and one complete case are presented. Data from the first two cases were obtained from individuals diagnosed with FAS who came before Judge Lafond in the Youth court and were documented. The data are presented below.

2.4.5.1 Case 1: 12 year old First Nations female

- diagnosed with FAS at age 3
- before Youth Court for the first time
- accepted responsibility for a series of arson offenses, setting two multi-unit residential buildings and 12 plastic dumpsters on fire (damages estimated at \$64,000 plus loss of residents' personal property)
- also accepted responsibility for shoplifting
- offenders disability was identified as a factor that should be considered in terms of public safety

- offender was denied access to one open custody facility in Saskatchewan because they “have reason to believe that she is at risk to be in a semi-secure environment”.
- Offender was in foster care for 1 year when she was 3 years of age
- Participated in solvent abuse with adults at her parents’ parties
- At the age of 10, the offender took a quantity of powerful tranquilizers
- Has been drinking and using drugs since the age of 8 or 9
- Does not attend school – was suspended for fighting and never returned
- Psycho-educational report indicates suggests that offender’s verbal ability was in the 16th percentile for age, mathematical ability was in the 27th percentile, recall of objects was below the 1st percentile. Coping skills were that of a 6 year old and language skills approximated those of a 7 year old. Despite these facts, however, the offender has never been involved in a special education environment and attended regular school.

2.4.5.2 Case 2: 13 year old First Nations male

- Diagnosed with FAS at 29 weeks old
- Came before the Youth Court to accept responsibility for four offenses: theft of a bicycle, two breaches of probation by failing to keep the peace and be of good behavior, and theft.
- Was found fit to stand trial via a psychological exam
- Has been through a variety of drug treatments to assist with behavioral problems
- Understanding was limited: could not define what “guilty” or “innocent” means
- Scored in the bottom 1 percentile on an intelligence test and in the 0.02 percentile for word comprehension and arithmetic
- Currently operating at a kindergarten level
- Since turning 12 years old, offender has been charged with 12 separate offenses and has made over 25 appearances in Youth Court

2.4.5.3 Case 3: Daniel Cutknife: 13-year old First Nations male

Data are presented based upon a retrospective and prospective analysis of costs involved in providing services to Daniel Cutknife – a 13-year old male diagnosed with Fetal

Alcohol Syndrome. Future costs were anticipated based upon the literature. The drinking history of the birth mother during her pregnancy with Daniel was self-recorded as a requirement for her employment and is represented by Figure 2.7. Daniel's utilization of services up to the age of 3 and their associated costs are illustrated by Table 2.2. It must be emphasized that this is a single case and data should be used only as a gross estimate of cost. Costs are all expressed as current value of past funds (for expenses already incurred) and of future costs (for expenses not yet incurred). The discount rate applied was 3%, which is similar to others used in the literature (Stade, 2003) and only activities that would be directly related to having FAS (i.e., that are beyond the normal experience of 4 Dr visit/year, etc) are included. Thus, data provide information about the *additional* costs related to FAS.

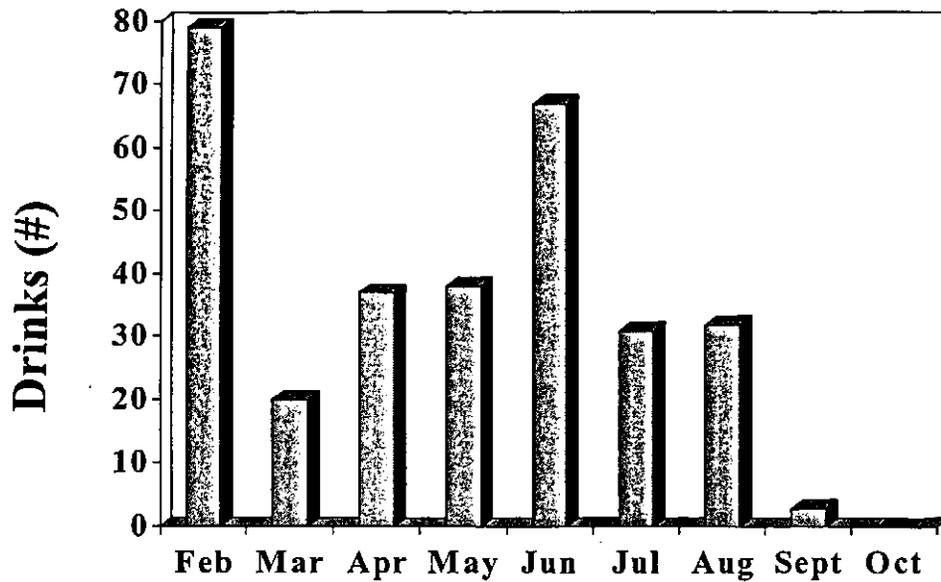


Figure 2.7: Alcohol Consumption During Pregnancy by a Birth Mother of an FAS Child. The number of drinks consumed on a monthly basis throughout gestation is shown in the figure above. The average number of drinks per occasion was: February: 9.9, March: 4, April: 6.2, May: 6.3, June: 6.7, July: 6.2, August: 6.4, September: 1.5, October: 0. The highest amount consumed on one occasion was 18 drinks. All drinks were consumed as beer. The average number of drinking days per month was 5.2, but ranged from 0-10 days.

Table 2.2: Case-Based Analysis of Estimated Lifetime Costs Associated with Having FAS

Age	Service/procedure	Cost	Number of Times Utilized	Adjusted Total
14 months	<ul style="list-style-type: none"> G-Tube operation stomach valve repaired 	\$6371.80	1	\$4469
8 years	<ul style="list-style-type: none"> plastic surgery on elf-shaped ears 	\$2332.10	1	\$2012
2-6 years	Tubes put in ears	\$788.00	5	\$2984
4-8 years	Caps on teeth	\$500.00	3	\$1211
2 months-6 years	<ul style="list-style-type: none"> Hospitalized for 1 week for bronchitis/pneumonia 	\$1991.95	4	\$6068
12 years	Braces	\$6500.00	1	\$6311
13 years	Eye surgery to correct wandering eye	\$2461.99	1	\$2462
13 years	Ear surgery to correct hearing loss	\$1827.40	1	\$1827
8 years	Hearing Aids	\$4000.00	2	\$6901
5-13 years	School Aid	\$15,000/year	7 years	\$93,454
6-13 years	Special Education	\$12,000/year	7 years	\$74,763
12 years	Respite Care	\$10,000/year	4 years	\$38,286
12 years	FAS Mentorship Program		weekly	
Birth-13 years	Emergency Room Visits	\$90	5	\$378
Birth-13 years	Family Dr visit	\$21.40	52	\$469

Extrapolations:

Age	Service/procedure	Cost	Number of Times Utilized	Adjusted Total
25 years	Ear surgery	\$1827	1	\$3020
25 years	Eye surgery	\$2461	1	\$4068
13-75 years	Family Dr visits	\$21.40	124 (4/year)	\$7715
25-37 years	Alcohol/Drug Rehab	\$2,415	90 day session	\$3443
25 years	Psychiatric Services	\$198/hr	144 (1/month for 12 years)	\$3474
25-37 years	Psychiatric Services for Family	\$198/hr	144 (1/month for 12 years)	\$3474
13-75 years	Emergency Room visit	\$90	15 (once/4 years)	\$2958
13-18 years	Special Education	\$12,000/yr	6 years	\$79,950
13-18 years	Special Education Aid Worker	\$15,000/yr	6 years	\$99,937
13-18 years	Social Worker	\$5,000/yr	6 years	\$33,312
25 years	Justice	\$233/day (adult and youth average)	90 days	\$29,898
30-60 years	Adult Assisted Living	\$12,000/yr	30 years	\$943,619
60 years - 75 years	Nursing Home	\$24,000/yr	15 years	\$1,750,805
TOTAL				\$3,309,794

This case-based methodology gives a much larger numerical estimate of some of the economic costs of FAS and FAE. Without correcting for the time-value of money, the straight estimate of economic costs measured was \$1.27 million. However, converting costs to present value yields a lifetime estimated cost of \$3.3 million (in today's dollars, assuming no inflation in prices for services and procedures). Taking these estimates and using estimates of incidence in Saskatchewan, it can be estimated that approximately \$33.5 billion would be needed to care for individuals and their families affected clinically by prenatal exposure to alcohol. It must be noted, however, that the case-based analysis evaluates cost estimates over the lifetime of *one* individual, and the other estimates measure costs to society per year. Even the case-based estimates may be underestimated, since children affected by prenatal alcohol exposure typically utilize social and justice services more heavily. On the other hand, FAE-affected individuals may not utilize the medical services to the same extent as those individuals with FAS

since they do not have the same degree (if any) of congenital malformations. However, taking these costs out of the calculation still yields a present value of \$3.29 million.

Calculating the cost to care for one individual based upon calculations using provincial budgets and estimated prevalence rates yields a figure of \$7300. Clearly, this is grossly underestimated, probably based on the fact that individuals with prenatal alcohol exposure over-utilize systems and services. However, without this type of information, accurate cost data cannot be determined. Nonetheless, these two different methodologies can be utilized to make very different estimates related to some of the economic costs associated with prenatal alcohol exposure. The case-based analysis calculates the total tangible lifetime cost of an individual with FAS (not adjusted for the time-value of money) to be \$1.2 million, which is close to published estimates of \$1.5 million (also not adjusted for the time-value of money). (Square, 1999)

2.4.6 Economic Cost Projections

It has been mentioned previously that, in Saskatchewan, FAS (and presumably FAE) occur in the highest frequency in Aboriginal populations, although exact numbers remain unknown. The growth rate of the Aboriginal population in Saskatchewan has been estimated to be 1.7% per year, while the population of the non-Aboriginal population is not changing. (Smith, 1997) Therefore, since Aboriginal populations appear to be more vulnerable to FAS and FAE and this population is growing in Saskatchewan, it can be expected that the prevalence of FAS and FAE will increase accordingly. Table 2.3 provides population projections for FAS and FAE in Saskatchewan from 2001-2021, assuming that population rates are changing at the same magnitude as they are today.

Table 2.3: Population Projections for FAS and FAE in Saskatchewan from 2001-2021 (number of people)

	2001	2003	2005	2007	2009	2011	2013	2015	2017	2019	2021
FAS	2,031	2,102	2,175	2,250	2,328	2,409	2,493	2,579	2,670	2,761	2,857
FAE	8,126	8,408	8,700	9,002	9,314	9,637	9,972	10,318	10,676	11,046	11,429
Total	10,157	10,510	10,875	11,252	11,642	12,046	12,465	12,897	13,346	13,807	14,286

Based upon projected growth rates for FAS and FAE in Saskatchewan (assuming patterns mimic those rates over the past 20 years), future costs for Saskatchewan Justice (Figure 2.8-2.10), Education (Figure 14), Health (Figure 15), and Social Services (Figure 16) are outlined below. In all cases, present values of monies were calculated using a discount rate of 3%. The inflation rate was assumed to be 1.5%, based upon the target rate by Statistics Canada. For calculations, please refer to Appendix VII.

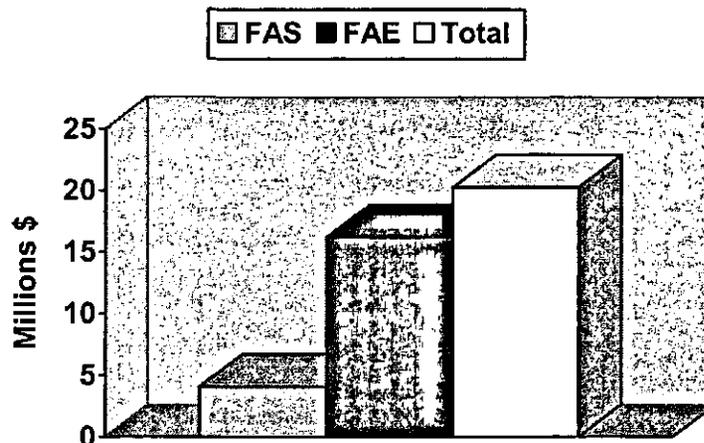


Figure 2.8: Estimated Projections of Custody-Associated Costs of FAS and FAE to the Saskatchewan Youth Offender System (2001-2021). Cost projections of custody-associated costs of FAS to Saskatchewan's Youth Offender System are estimated to be \$540,000/year by 2021 and costs of FAE \$11.5 million/year in 2021. The total cost of prenatal alcohol exposure to Saskatchewan's Youth Offender System can be estimated as \$12 million/year by 2021.

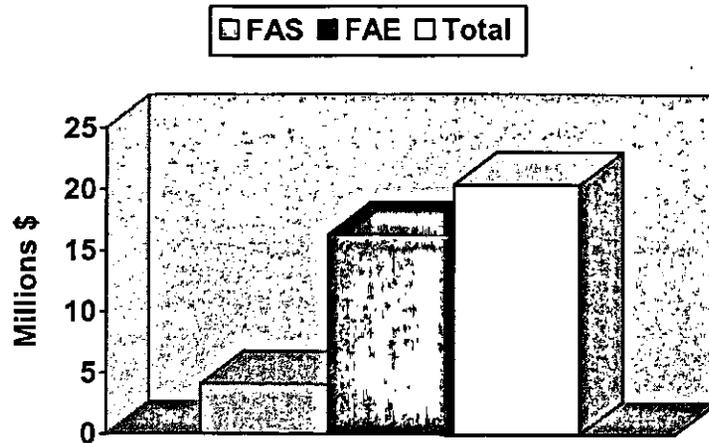


Figure 2.9: Estimated Projections of Custody-Associated Costs of FAS/FAE to Adult Corrections in Saskatchewan (2001-2021). Cost projections of custody-associated costs of FAS to Saskatchewan's Adult Corrections System are estimated to be \$51,000/year by 2021 and costs of FAE \$10.8 million/year in 2021. The total cost of prenatal alcohol exposure to Saskatchewan's Youth Offender System can be estimated as \$11.3 million/year by 2021.

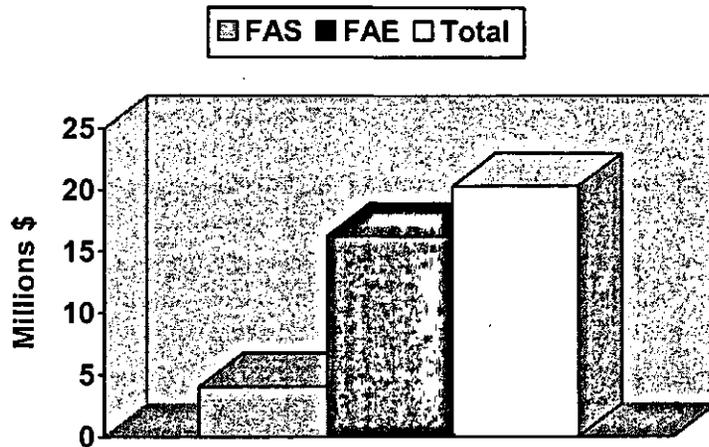


Figure 2.10: Estimated Projections of Custody-Associated Costs of FAS/FAE to Corrections in Saskatchewan (2001-2021). Cost projections of custody-associated costs of FAS to Saskatchewan's Justice System (Youth and Adult Corrections) are estimated to be \$2.8 million/year by 2021 and costs of FAE \$59.4 million/year in 2021. The total cost of prenatal alcohol exposure to Saskatchewan's Justice System can be estimated as \$62.2 million/year by 2021.

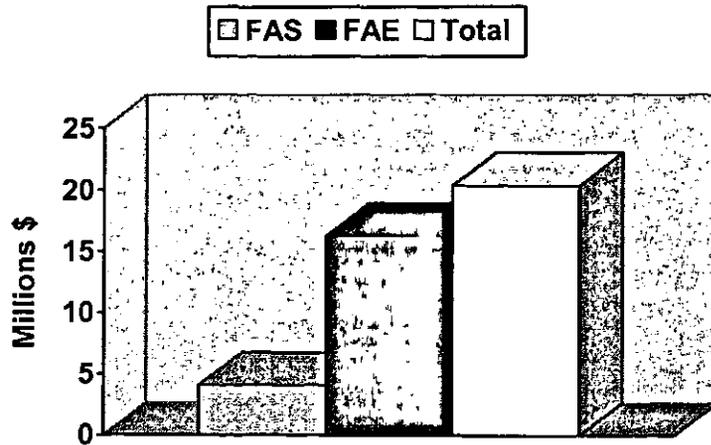


Figure 2.11: Estimated Cost Projections of FAS/FAE to Education in Saskatchewan (2001-2021). Cost projections of FAS to Saskatchewan’s Education System are estimated to be \$180,000/year by 2021 and costs of FAE \$740,000/year in 2021. The total cost of prenatal alcohol exposure to Saskatchewan’s Education System can be estimated as \$920,000/year by 2021.

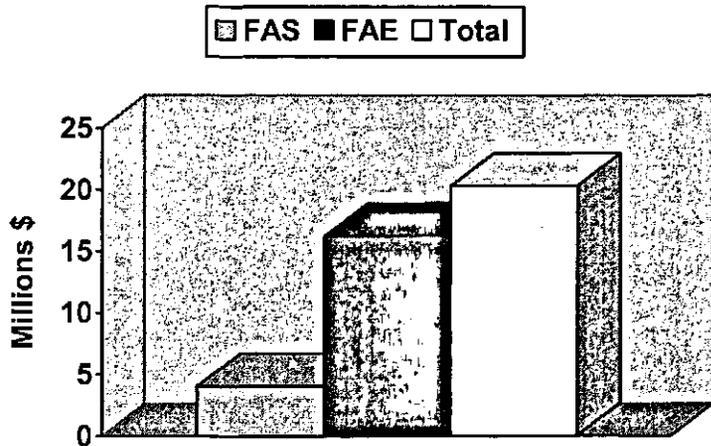


Figure 2.12: Estimated Cost Projections of FAS/FAE to Health in Saskatchewan (2001-2021). Cost projections of FAS to Saskatchewan’s Health System are estimated to be \$15.1 million/year by 2021 and costs of FAE \$57.3 million/year in 2021. The total cost of prenatal alcohol exposure to Saskatchewan’s Health System can be estimated as \$72.4 million/year by 2021.

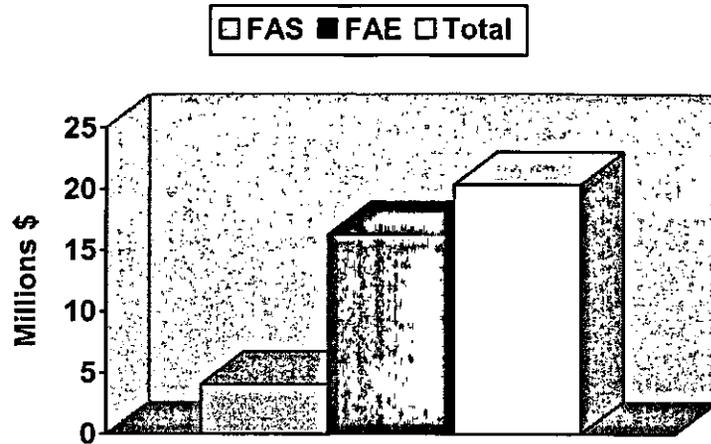


Figure 2.13: Estimated Cost Projections of FAS/FAE to Social Services in Saskatchewan (2001-2021). Cost projections of FAS to Saskatchewan Social Services are estimated to be \$4.5 million/year by 2021 and costs of FAE \$16.6 million/year in 2021. The total cost of prenatal alcohol exposure to Saskatchewan Social Services can be estimated as \$21.1 million/year by 2021.

Total projected costs of FAS and FAE to Saskatchewan are anticipated to reach \$109.3 million by 2021. The time-series relationship is illustrated by Figure 2.14.

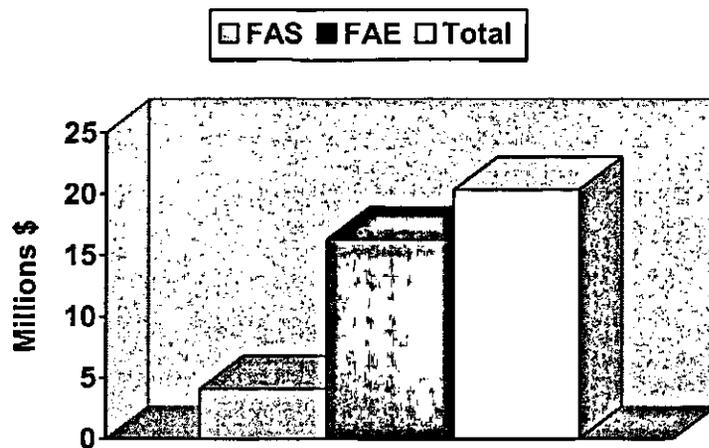


Figure 2.14: Some Estimated Cost Projections of FAS/FAE for Saskatchewan (2001-2021). Cost projections of FAS to Saskatchewan Justice, Education, Health and Social Services are estimated to be \$22.6 million/year by 2021 and costs of FAE \$123.2 million/year in 2021. The total cost of prenatal alcohol exposure to Saskatchewan Justice, Education, Health and Social Services can be estimated as \$145.8 million/year by 2021.

At present, Statistics Canada reports the population of Saskatchewan to be 1.02 million. (Statistics Canada, 2002) Based upon this population measure, the number of individuals affected by prenatal alcohol exposure can be extrapolated to be 2040 and 8160 respectively for FAS and FAE, based upon prevalence rates of 0.2% and 0.8% for FAS and FAE, respectively. Given the fact that lifetime care of 1 individual is most realistically estimated to be \$3.3 million in this study, in today's dollars, (excluding the costs of intangible measures), conservative estimates with respect to some costs associated with FAS to Saskatchewan is \$6.7 billion and is \$26.8 billion for FAE. (FAE costs can be extrapolated from costs associated with FAS, corrected for the absence of congenital facial abnormalities).

A small reduction in the utilization of services associated with special education, justice, health, and social services by 10% (it is assumed that a reduction in utilization results in a proportional reduction in associated cost) can be a significant cost-savings to Saskatchewan in the future years (Table 2.4).

Table 2.4: Estimated Cost Savings

Reduction in Service Utilization	Savings 2001 (\$millions)	Savings 2005 (\$millions)	Savings 2009 (\$millions)	Savings 2013 (\$millions)	Savings 2017 (\$millions)	Savings 2019 (\$millions)
10%	4.1	5.4	6.9	8.9	11.4	12.9
25%	10.3	13.5	17.3	22.2	28.4	32.2
50%	20.5	27.1	34.7	44.4	56.9	64.4
75%	30.8	40.6	52.0	66.6	85.3	96.6

2.5 Discussion

It is evident, even based upon these cost estimates and projections presented, that FAS and FAE cost the province and people of Saskatchewan a significant amount of dollars every year. In 2001, conservative estimates (using provincial budgets) suggest that the total cost of FAS to the province was \$6 million and that of FAE was \$35 million, bringing the total cost for caring for individuals currently affected by prenatal alcohol exposure to \$ 41 million per year.

Data, however, do not include the fact that FAS/FAE individuals are at higher risk for substance abuse, prostitution, unwanted and teenage pregnancies, and the need for assisted living programs. (Streissguth, 1996) Social costs not analyzed in this study include a number of opportunity costs: the poor quality of life of the individual with FAS/FAE and their families/caregivers and lost income of the individual and of the stay-at-home caregiver (in most cases, an adoptive mother).

Data suggest that the most significant economic costs for Saskatchewan are associated with Health. Studies indicate that, not surprisingly, mental health services are

disproportionately utilized by FAS and FAE individuals and their families and caregivers (Streissguth, 1977; Olson *et al.*, 1998) and this, undoubtedly, is where a large fraction of the Health monies are spent. By designing better intervention programs aimed at improving outcomes for affected individuals and their communities, health care costs could be significantly reduced. For example, by offering counseling services early in the lives of affected children and their families and by helping them to learn to accept and to adapt to their condition and situation, the lifetime need for continuing psychiatric surveillance could be alleviated because early intervention has been shown to significantly decrease the development of secondary disabilities associated with prenatal alcohol exposure. (Streissguth *et al.*, 1997; Streissguth, 1997; Streissguth and Kanter, 1997; Astley and Clarren, 1999)

Other significant health costs would be predicted to be associated with the congenital malformations associated with FAS (for a brief outline, please refer to Table 2.2, page 47). Intervention programs cannot reduce these costs. However, emergency visit costs resulting from violence and victimization associated with prenatal alcohol exposure could be significantly reduced by programs aimed at teaching life skills because this could reduce vulnerability of FAS/FAE affected individuals.

The impact of FAS and FAE on the justice system is the subject of much discussion. One study showed that 61% of FAS adolescents had run afoul with the law at least once, most frequently, involving shoplifting and theft. (Streissguth, 1996) A recent report in Saskatchewan estimates that as many as half the young offenders appearing in provincial court suffer from FAS; The study found that FAS offenders were rarely motivated by malice but were more likely to have been exploited by smarter, more savvy criminals. (Zakreski, 1998) The case studies presented also suggest that even young individuals affected by prenatal alcohol exposure are repeat offenders and are not rehabilitated through correctional services. Appropriate programs geared specifically toward rehabilitation of FAS/FAE-affected individuals would potentially mitigate the repeat offenses and would be a significant cost-savings to the both youth and adult justice programs.

The results of this study suggest that additional funding is required to ensure that all children clinically affected by prenatal alcohol exposure that would benefit from access to special education programs. The data also suggest that alcohol-related diagnoses be recorded in the records of the individual so measures of both need for services and economic impact can be assessed. By having access to specialized education services, individuals may progress better academically and their education-related costs will be mitigated in the short-run while other related costs to society may be mitigated in the long-run (i.e., loss of income because of inability to be gainfully employed).

Costs of FAS to Social Services are also significant because of the disproportionate utilization by affected children and their families. When children are diagnosed with FAS or FAE, they are typically assigned a social worker for assistance. If undiagnosed but the child is suspected (usually by teachers or by the youth court) to have disabilities congruent with prenatal alcohol exposure, referral for diagnosis and to intervention services may occur. Clearly, the evidence is strong for improved outcome associated with access to early intervention programs, (Streissguth *et al.*, 1997; Streissguth, 1997; Streissguth and Kanter, 1997; Astley and Clarren, 1999) and by utilizing these services, the need for extensive involvement by Saskatchewan Social Services may be ameliorated and monies would be saved in the long term.

2.6 Summary

In summary, costs estimated to be associated with FAS and FAE are significant to Saskatchewan. Data from the literature suggests that multifaceted intervention programs for children with FAS and FAE diagnoses, initiated as early as possible in their lifetime and continuing throughout adulthood are crucial to improve outcome. (Streissguth *et al.*, 1997; Streissguth, 1997; Streissguth and Kanter, 1997; Astley and Clarren, 1999) With improved outcome comes decreased utilization of services associated with health, social services, justice, and education that translates into cost-savings in the long-run.

FAS and FAE are costly at present and associated costs can be expected to increase, based upon the anticipated expected growth in the number of individuals exposed prenatally to alcohol in Saskatchewan's population. These are conservative estimates, since 1) underdiagnosis is probably a significant issue and has not been accounted for (see Chapter 3), and 2) prenatal alcohol exposure tends to be an inter-generational cycle, since affected individuals are at increased risk for substance abuse, victimization, and unplanned pregnancies. Thus, the growth rate might be underestimated as well. Obviously, to make accurate economic predictions and measurements, true prevalence rates, rates of service utilization, as well as the demographic and geographic distribution of FAS and FAE must be determined in Saskatchewan. In order for this to occur, screening for suspect cases and referrals for alcohol-related diagnoses must be made. Affected individuals must be labeled with their diagnosis in provincial databases. Understanding the economic costs associated with FAS and FAE are key to determining the most effective use of monies provided for the development of targeted prevention and intervention programs.

3.0 Study 2: Knowledge and Attitudes of Family Physicians Towards FAS and FAE in Saskatchewan

3.1 Introduction

Although there has been increased attention focused on alcohol's negative effects on fetal growth and development in recent years, previous surveys suggest disparity in the knowledge, attitudes, practices and training requirements of physicians with respect to prenatal alcohol exposure. Data from the United States, (Abel and Kruger, 1998) from Alberta, (Clarke, 1999) Toronto, (Nevin *et al.*, 2002) and Saskatchewan (Nanson *et al.*, 1995) suggest that 1: health care professionals still require education and training with respect to FAS and its related diagnoses, and 2: FAS/FAE is underdiagnosed. Given that the importance of early intervention for improving the quality of life for affected individuals and their families (See Chapter One for discussion) is dependent upon early diagnosis, the under-diagnosis of FAS is of concern.

In 1992, Saskatchewan physicians were surveyed on their knowledge and attitudes toward FAS. (Nanson *et al.*, 1995) This study suggested that Saskatchewan physicians were aware of FAS but expressed a need for more information about FAS, particularly for parents. They also expressed a need for physician training materials and information about where to refer patients with FAS and parents with alcohol-related problems. (Nanson *et al.*, 1995) These data were similar to results reported from a recent survey of Toronto physicians. (Nevin *et al.*, 2002) Since FAS appears to be presently under-diagnosed (or under-reported) in Saskatchewan (See Chapter 2) despite the efforts of public and health professional awareness campaigns, it is unclear whether there have been any changes in physicians' knowledge of, attitudes toward, and frequency of diagnosis of FAS in the past 10 years.

3.2 Objective and Hypotheses

This study was designed to determine the level of knowledge of Saskatchewan general practitioners with respect to FAS and FAE and their practices related to the diagnosis of alcohol-related disabilities. General practitioners were determined to be the most appropriate group to sample since there only 41 pediatricians in Saskatchewan and Saskatchewan's population (including children) is predominately served by general practitioners. In general, it is hypothesized that physicians require more education and training with respect to FAS/FAE to make accurate diagnoses and to most effectively care for affected individuals and their families.

3.2.1 Specific Hypotheses

The specific hypotheses, states in their null alternative, are as follows:

1. Saskatchewan general practitioners are not knowledgeable about FAS.

To determine whether Saskatchewan general practitioners are knowledgeable about FAS, their responses to Questions 32 (In your opinion, do the following characteristic define FAS?) and 34 (Please indicate whether the following, in your opinion, are associated with or are directly caused by FAS) will be evaluated using a frequency analysis. For all questions, identifying 80% of the answers correctly will earn the label "knowledgeable". This is the same standard used on the National survey conducted by Health Canada in 2001-2002.

2. Saskatchewan general practitioners are not knowledgeable about the criteria and currently accepted procedures to make an accurate FAS diagnosis

To determine whether Saskatchewan general practitioners are knowledgeable about the criteria and procedures to make an accurate FAS diagnosis, their responses to Questions 32 (In your opinion, do the following characteristics define FAS?) and 33 (Which of the following items would give you the most accurate information regarding the diagnosis of FAS?) will be evaluated using a frequency analysis. Respondents must identify all cardinal features correctly to be considered "knowledgeable" for Question 32 and must identify "the combination of growth, brain, and facial abnormalities" OR "mother has a

history of alcohol abuse or dependency” to be considered knowledgeable for Question 33.

3. Saskatchewan general practitioners are not knowledgeable about FAE.

To determine whether Saskatchewan general practitioners are knowledgeable about FAE, their responses to Question 5 (Please indicate your opinion on the following statements. The term FAE.....) will be evaluated using a frequency analysis.

4. Saskatchewan general practitioners knowledgeable about FAS are also knowledgeable about FAE.

In order to determine if Saskatchewan general practitioners who are knowledgeable about FAS are also knowledgeable about FAE, the number of respondents who were knowledgeable of the cardinal features of FAS (Question 32) and the general characteristics of FAE (Question 5) will be determined by a Chi-Square analysis. The Scheffe test was used for multiple comparisons because it is conservative and protects against the risk of Type 1 error.

In cases where the assumptions underlying Analysis of Variance were violated, non-parametric tests were performed. In all cases, results were the same as those obtained using conventional measures.

5. FAS was identified as a syndrome in 1973 and other forms of alcohol-related birth defects began to be recognized in the 1980's. A number of Canadian medical schools have begun to incorporate information about FAS into their curricula. Thus, it is hypothesized that the most recent graduates (those graduating from 1990-2001) would be the most knowledgeable about FAS.

To test these hypotheses, the graduation year for those respondents who are knowledgeable about FAS (Question 32) will be evaluated for year of graduation by a one-way Analysis of Variance with post-hoc analyses by Scheffe Test.

6. Alcohol-related disorders appear to be more prevalent in rural areas (May *et al.*, 2000) but information may be more readily available and accessible in urban settings. Thus, it is of interest to determine if place of practice has an effect on knowledge about FAS. It is hypothesized that Saskatchewan general practitioners practicing in rural areas are more knowledgeable about FAS than urban practitioners.

In order to determine if Saskatchewan general practitioners from rural areas are more knowledgeable about FAS diagnostic criteria than urban respondents, a Chi-Square analysis will be performed for place of practice on those respondents who are knowledgeable about the cardinal features of FAS (Question 32).

7. Saskatchewan's general practitioners do not feel prepared to care for pregnant women in the area of alcohol abuse.

To determine the level of comfort of Saskatchewan's general practitioners to care for pregnant women in the area of alcohol abuse, responses to Question 9.1.1 (How prepared do you feel to care for the following groups of clients in the area of alcohol abuse or dependency? Pregnant women.....). Responses will be analyzed by frequency analysis.

8. It is of interest to determine if knowledge and attitudes of Saskatchewan practitioners has changed over the past 10 years. Time-dependent trends in knowledge will be determined by qualitative comparisons with Nanson's published survey data from general practitioners in 1992. (Nanson *et al.*, 1995)

3.2.2 Implications

These data will provide evidence as to whether physicians feel comfortable making an alcohol-related diagnosis, whether they have the knowledge and training to do so, and whether they feel prepared to care for women with respect to drinking alcohol during pregnancy. Results will determine what physicians perceive to hinder their ability and/or confidence to make accurate diagnoses of FAS and FAE as well as to care for pregnant women consuming alcohol. The findings will give also provide insight with

respect to the possibility of under-diagnosis in Saskatchewan. By learning what physicians perceive as their needs to feel comfortable with making alcohol-related diagnoses, programs can be developed targeted to the specific needs of general practitioners. The long-run effects of these programs may include an increased frequency of accurate diagnoses/referrals for FAS and FAE, increased comfort levels of physicians to offer early interventions to pregnant women who may be consuming alcohol during pregnancy, and finally, the eventual ability to determine accurate rates of incidence and prevalence. By comparing data from a similar survey administered to Saskatchewan physicians in 1992, changes in knowledge and attitudes toward FAS over a 10-year period can be determined.

3.3 Methodology and Data Collection

Surveys (Appendix VIII) were mailed to approximately half (400) of Saskatchewan's general practitioners along with a cover letter explaining the nature of the study (Appendix IX). Recipients were randomly selected from a list provided by the Saskatchewan Medical Association. This methodology allowed a reasonable number of physicians to be sampled for all areas of the province and across all years of graduation. Surveys were coded with a bar code to protect identities and to maintain confidentiality. Physicians were given a two week period in which to return surveys and then another identical set of surveys was mailed to the non-respondents with a follow-up cover letter (Appendix X). Physicians, again, were given a two week period for return of the survey with the added incentive of being entered into a draw for a \$50 gift certificate for Chapters Online. A third round of surveys was sent to the non-responders, and an additional 2-week period was allowed for the response. The cover letter was identical to that used in the second round. Surveys that were returned blank were considered to be refusals and were not included in the study. Data from completed surveys were entered into a database (Microsoft Excel) for statistical analysis (see below).

Survey questions were identical to those currently being utilized by Health Canada in a National survey and were similar to a survey administered in 1995 by Nanson *et al.*

(Nanson *et al.*, 1995) (Appendix XI). Data were analyzed using the Frequency and Chi-Square tests for categorical data, with the level of significance of 0.01 to correct for the large number of comparisons. Where appropriate, non-parametrical comparisons were performed. In all cases, results from these tests did not differ from the parametrical analyses. Data were compared to the Nanson survey results in a descriptive manner, since the original dataset from the earlier survey was unavailable.

Where possible, data were compared to the Nanson survey results (Nanson *et al.*, 1995) to analyze changes in knowledge over a 10-year period. All questions deemed to be of significance to this study were identical between the two surveys.

3.4 Results

3.4.1 Physician Characteristics

One survey was returned by the postal service in the first round with an incorrect address and twenty were returned in the second round. A total of 113 (28%) of the family physicians surveyed completed the questionnaire. Some did not respond (n=284: 72%) and, of these, 11 (3%) returned the survey blank. Response rates are outlined in Table 3.1.

Table 3.1: Survey Response Rates

	Number	Percent (%)
Sampled	399	100
Responders	113	28.3
Non-Responders	286	71.7

Physician characteristics of responders are illustrated in Table 3.2.

Table 3.2: Physician Characteristics* of Respondents

	Number
Male	77 (73%)
Mean Age	48.4 ± 1.2 years
Female	29 (27%)
Mean Age	46.4 ± 2.1 years
Mean Age of all Respondents	47.8 ± 1.1 years
25-34 years	13 (12%)
35-44 years	33 (31%)
45-54 years	31 (28%)
55-64 years	20 (19%)
> 64 years	9 (8%)
Year of Graduation:	
1950-1973	29 (28%)
1974-1989	46 (45%)
1990-2001	28 (27%)
Primary Mode of Practice	
Solo	27 (26%)
Group	71 (68%)
Other	7 (7%)
University Appointment	34 (30%)
Urban practice	56 (50%)
Rural practice	56 (50%)

*only 106 participants answered all questions pertaining to physician characteristics.

3.4.2 Awareness and Identification of FAS and FAE

3.4.2.1 General Awareness

Only 3% (n=3) of respondents recently heard of FAS (in the last year or two), while most have been aware of it for more than four years (93%; n=99). Sources of information included mass media (37%; n=39), parents/patients (19%; n=20), colleagues (43%; n=45), CME seminars and rounds (56%; n=59), medical journals or books (73%; n=77), medical school, residency, or fellowship (59%; n=62). Similarly, the majority of

the physicians became aware of FAE in more than four years ago (50%; n=53), but some became aware of it three to four years ago (14%; n=14) and even in the last year or two (21%; n=22). Fourteen per cent reported that they had never heard of the term (n=14). Knowledge of FAE was gained through mass media (19%; n=20), parents/patients (11%; n=11), colleagues (34%; n=36), CME seminars and rounds (45%; n=47), medical journals or books (65%; n=68), medical school, residency, or fellowship (16%; n=16). The majority of the physicians correctly perceived that the incidence of FAS in Canada was higher than the incidences of Down's syndrome (77%; n=81), spina bifida (75%; n=79), cerebral palsy (58%; n=61) and juvenile diabetes (52%; n=55) but lower than the incidence of asthma (85%; n=90).

3.4.2.2 Identification of FAS

Most respondents thought that FAS is indeed an identifiable syndrome (37%; n=39 strongly agreed and 60%; n=63 agreed), and they generally believed that the effects of alcohol on fetal development are identifiable (80%; n=84). They identified a role for physicians in managing problems associated with alcohol use (69%; n=73) and recognized that FAS occurs in all strata of society (86%; n=91). However, the majority of the physicians disagreed with the statements that FAS occurs at similar rates among all cultures and ethnic groups (75%; n=79), disagreed that discussing the use of alcohol during pregnancy will frighten or anger patients (92%; n=97), and disagreed that discussing alcohol use during pregnancy will deter women from seeking/continuing treatment (80%; n=84). They also reported that they disagreed with the statement that making a diagnosis of FAS does not change anything for the child (82%; n=86) but agreed that prenatal exposure to alcohol is a significant risk factor for permanent brain damage (86%; n=91).

89% (n=94) report that they ask all pregnant women about drinking alcohol during pregnancy.

3.4.2.3 Identification of FAE

With respect to FAE, there is some uncertainty among physicians about the term. They tend to believe that FAE denotes a less severe form of FAS (75%; n=79) and that this term is used in the absence of facial dysmorphology (52%; n=55) and if the patient shows only partial expression of FAS (73%; n=77). All responses are shown in Table 3.3.

Table 3.3: Physician Responses to their Beliefs About FAE

	Percent of Respondents Indicating the Belief
Denotes a less severe form of FAS	75% (n=79)
Used in the absence of facial dysmorphology	52% (n=55)
Used if the patient shows only partial expression of FAS	73% (n=77)
Used if the child is too young to make an FAS diagnosis Age	32% (n=33)
Used when birth defects from prenatal exposure diminish over time	24% (n=25)
Used when there are no IQ deficits	33% (n=34)
Used if the child has birth defects but maternal alcohol use history is unclear	36% (n=38)
Used when the child demonstrates only behavioral components of the syndrome	37% (n=39)
Results in better long-term social outcomes than if the term FAS is used	49% (n=51)

3.4.3 Knowledge of FAS and FAE

3.4.3.1 General Knowledge of FAS

Only 16 of all respondents (15%) correctly identified 80% of the general facts about FAS in Question 34, and thus the majority lacked the adequate level of knowledge.

3.4.3.2 FAS Diagnosis

Of all physicians responding, 36% (n=40) report having diagnosed FAS, 58% (n=65) have cared for an FAS patient, 54% (n=61) suspected but did not diagnose FAS, and 47% (n=53) referred patients to confirm a diagnosis of FAS.

There are specific cardinal features of FAS that define the syndrome and are the characteristics upon which a diagnosis is based. Thus, the ability to identify these cardinal features would be an indication of ability to diagnose FAS. All physicians could identify at least one of the cardinal features of FAS. Figure 3.1 shows the proportion of physicians recognizing the cardinal features of FAS.

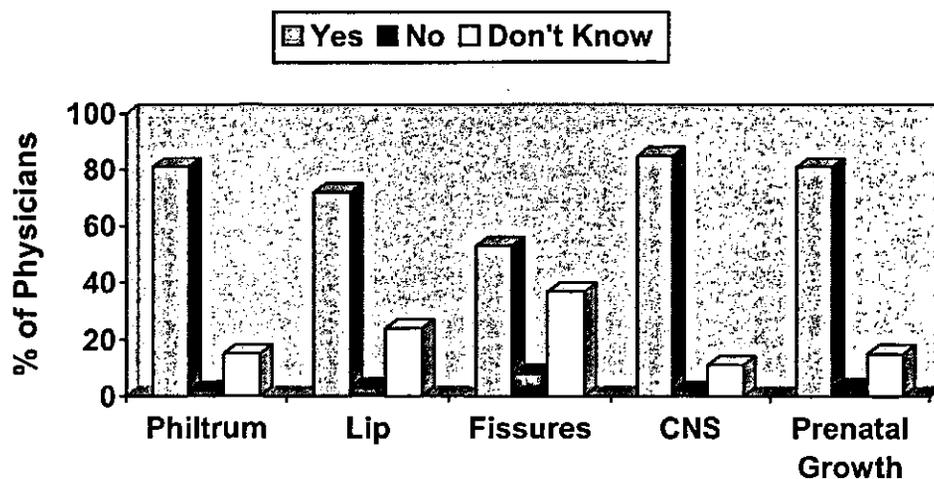


Figure 3.1: Responses to the Identification of the Features of FAS. Percentage of physicians that answered Yes, No, or Don't Know when asked to identify the features of Fetal Alcohol Syndrome.

Only 13 respondents (11%) identified all features correctly. These respondents were deemed to be "knowledgeable" for the purpose of further discussion and analysis in this thesis. Of those unknowledgeable of FAS, an additional 16 (16%) endorsed the cardinal features plus one additional non-related one.

Another corroborating variable was used as an indicator of diagnostic knowledge – ability to identify the categories of features (maternal alcohol use, or a combination of facial, neurobehavioral, and growth deficits) that would give the most knowledge about a diagnosis. Of the 13 knowledgeable of FAS cardinal features for diagnosis, 12 (92%) also correctly identified the diagnostic procedure. However, knowledge of the diagnostic features was unrelated to knowledge of general information about FAS, since only 3 respondents (23%) scored “knowledgeable” on both sets of questions (Questions 32 and 34).

In terms of use of diagnostic schema, only 8% (n=9) of the respondents make use of one. However, none of the knowledgeable physicians reported using one. Figure 3.2 illustrates the breakdown of the schema used.

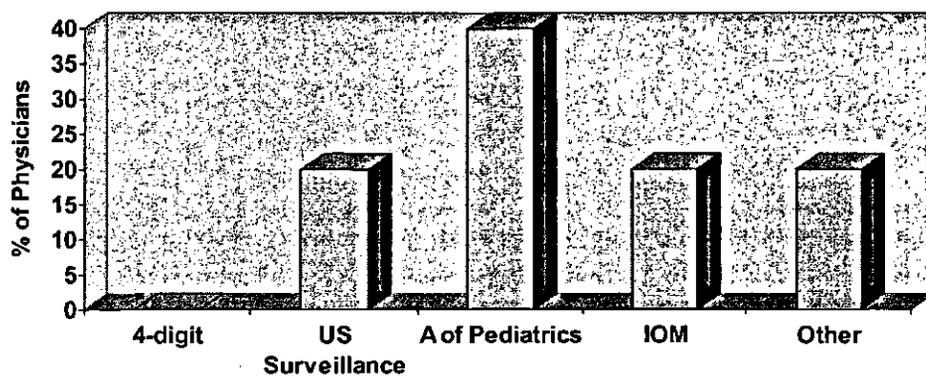


Figure 3.2: Diagnostic Schema Utilized. Types of diagnostic schema used by physician respondents who report utilization with respect to FAS and FAE diagnosis/referral. The US Surveillance system is most commonly utilized. A of Pediatrics = Association of Pediatrics; IOM = Institute of Medicine.

The “other” diagnostic schemae were reported by two respondents and were described as “clinical features and history” and the “LMCII test”.

Unfortunately, some physicians have identified that access to others who may be able to assist in diagnosis are not available in their communities. More specifically,

psychologists (6%; n=6), educational information (2%; n=2), a multidisciplinary team (12%; n=12), an outreach clinic (23%; n=24), CME training (4%; n=4), and Telehealth (19%; n=20) are not available, although the majority of physicians report that all these features would be helpful for making an FAS diagnosis (Table 3.4).

Table 3.4: Helpfulness of Resources in Making an FAS Diagnosis

Service	Helpful	Not Helpful	Not Available
Psychologist	80% (n=84)	11% (n=11)	6% (n=6)
Educational Information	89% (n=94)	8% (n=8)	2% (n=2)
Multi-disciplinary Team	86% (n=91)	2% (n=2)	12% (n=12)
Outreach Clinic	72% (n=76)	4% (n=4)	23% (n=24)
CME Training	93% (n=98)	2% (n=2)	4% (n=4)
Telehealth	54% (n=57)	26% (n=27)	19% (n=20)

3.4.3.3 Knowledge of FAE

Only 10/115 (9%) respondents correctly identified all features of FAE in Question 5 and were therefore categorized as knowledgeable about FAE. FAS knowledge (as determined by correct identification of the cardinal features in Question 32) was not related to FAE knowledge [$X^2(1) = 0.7, p = 0.4$]. Only 3 (23%) of those knowledgeable of FAS were also knowledgeable of FAE. (For additional statistics, please refer to Appendix XII, Table 1)

3.4.3.4 Effects of Graduation Year

One-way Analysis of Variance suggests that knowledge of FAS was unrelated to year of graduation from medical school [$F(2) = 3.76, p = 0.27$] when year of graduation was transformed into a categorical variable: Graduated before 1973 (n=29), Graduated between 1973-1989 (n=46), Graduate after 1990 (n=28). Twelve participants did not provide data for year of graduation. Two of the knowledgeable respondents (15%) graduated before 1973 and an additional two graduated after 1990 (15%), while 9 (70%) graduated between 1950 and 1989. Of the unknowledgeable, 27 respondents (30%)

graduated before 1973, 37 (41%) graduated between 1950 and 1989, and 26 (29%) graduated after 1990. (For additional statistics, please refer to Appendix XII, Table 2)

There was a not a significant effect of graduation year on FAE knowledge when data were analyzed by another one-way Analysis of Variance [$F(2)= 3.049, p=0.052$]. Overall trends in responses paralleled those of the knowledgeable respondents; the greatest number of respondents graduated between 1973 and 1990 (46% for the knowledgeable and 45% for the unknowledgeable), while fewer graduated prior to 1973 (27% for the knowledgeable and 28% for the unknowledgeable) and after 1990 (27% for of both knowledgeable and unknowledgeable respondents). (For additional statistics, please refer to Appendix XII, Table 3)

3.4.3.5 Effects of Place of Practice

Knowledge of FAS was unrelated to place of practice [$X^2(1)=0.79, p=0.37$]. Of those who were knowledgeable (n=13), most were practicing in an urban environment (8 of 13, or 62%); of the unknowledgeable (n=89), the urban/rural split was equal (48% vs 52%, respectively). Still, it is important to note that the majority of both urban practitioners (90%) and rural practitioners (89%) were unknowledgeable about FAS features. (For statistics, please refer to Appendix XIII, Table 4)

Knowledge of FAE was not related to place of practice [$X^2(1)=0.102, p=0.75$]. 50% (n=5) of those knowledgeable about FAE identified themselves as having an urban practice, and 50% (n=5) identified their practice to be rural. Of the unknowledgeable, 49% (n=51) practiced in an urban environment and 51% (n=53) practiced in a rural area. (For additional statistics, please refer to Appendix XII, Table 5)

However, there was a significant difference in the percentage of rural and urban practitioners who report having diagnosed FAS [$X^2(1)=6.6, p=.01$]. Rural practitioners report having diagnosed FAS at over twice the rate of the urban ones since 23 (46%) of the rural vs. only 10 (21%) of the urban practitioners report having diagnosed FAS. (For additional statistics, please refer to Appendix XII, Table 6)

There were no significant effects of place of practice with respect to caring for a patient with FAS [$X^2(1)=0.2$, $p=0.66$], with 60% ($n=33$) of urban physicians and 56% ($n=31$) of rural physicians reporting having cared for an individual with FAS. Similarly, there were no significant urban/rural distinctions for having suspected but not diagnosed FAS [$X^2(1)=0.07$, $p=0.78$] and for the tendency to refer patients to confirm an FAS diagnosis [$X^2(1)=1.3$, $p=0.25$]. (For additional statistics, please refer to Appendix XII, Table 7)

3.4.3.6 Effects of University Appointment

Knowledge of FAS was also not significantly related to having a university appointment [$X^2(1)=0.588$, $p=0.443$]. Of the 30 individuals with a university appointment, 5 (17%) were knowledgeable. Of the 72 non-university appointees, 8 (11%) were knowledgeable about FAS. Of those who were not knowledgeable, 25 (28%) had a university appointment while 64 (72%) did not. (For additional statistics, please refer to Appendix XII, Table 8)

Having a university appointment did not affect knowledge level of FAE. Chi-Square analysis revealed a non-significant effect of university appointment on ability to correctly identify features of FAE [$X^2(1)=0.440$, $p=0.509$]. Of the knowledgeable, 5 (46%) had a university appointment and 6 (54%) did not. Of the unknowledgeable, 25 (28%) had a university appointment and 66 (72%) did not. (For additional statistics, please refer to Appendix XII, Table 9)

3.4.3.7 Feelings of Preparedness

In general, respondents felt prepared (48%; $n=50$) or very prepared (12%; $n=12$) to care for pregnant women in the area of alcohol abuse or dependency, but some also reported feeling unprepared (32%; $n=33$). They felt equally prepared and unprepared to care for birth mothers (45% felt prepared; $n=47$, 55% felt unprepared; $n=58$), foster parents (55% felt prepared; $n=58$, 45% felt unprepared; $n=47$), and individuals affected by FAS/FAE (52% felt prepared; $n=55$, 48% felt unprepared; $n=50$) with respect to alcohol abuse.

Feeling prepared to care for pregnant patients in the area of alcohol abuse was not dependent upon year of graduation [$X^2 (2) = 1.19, p=0.552$], University appointment [$X^2 (1)=0.292, p=0.589$], or place of practice [$X^2 (1)=1.95, p=0.163$]. Specific data are illustrated in Table 3.5. For additional statistics, please refer to Appendix XII, Table 10.

Table 3.5: Effects of Place of Practice, University Appointment, and Year of Graduation on Feelings of Preparedness to care for Pregnant Women in the area of Alcohol Abuse

	Prepared	Unprepared
Per Cent of Survey Respondents	68% (n=72)	32% (n=33)
Rural	56% (n=59)	42% (n=44)
Urban	44% (n=46)	58% (n=61)
University Appointment	32% (n=33)	68% (n=72)
No University Appointment	29% (n=30)	71% (n=75)
Graduated before 1973	25% (n=26)	33% (n=34)
Graduated between 1973 & 1990	49% (n=51)	39% (n=41)
Graduated after 1990	26% (n=27)	28% (n=29)

3.4.3.8 Comparison of Physicians' Knowledge and Attitudes Toward FAS in Saskatchewan from 1992 - 2002

Data are compared to the trends identified by Nanson *et al.* from physicians surveyed in 1990-1991 (Nanson *et al.*, 1995) in Table 3.6.

Table 3.6: Comparison of Physicians' Knowledge and Attitudes Toward FAS in Saskatchewan from 1992 - 2002

	1992 (n=249)	2002 (n=106)
Awareness of FAS		
CNS Dysfunction	93% (n=231)	96% (n=101)
Facial Features	91% (n=226)	88% (n=93)
Growth Retardation	96% (n=239)	91% (n=96)
Sources of Knowledge		
Mass media	33% (n=82)	39% (n=41)
CME courses	56% (n=139)	56% (n=59)
Medical journals	71% (n=176)	73% (n=77)
Medical school training	54% (n=134)	58% (n=61)
Patients/Parents	15% (n=37)	19% (n=20)
Diagnosed FAS	43% (n=107)	35% (n=37)
Referred Patients for Diagnosis	30% (n=74)	41% (n=43)
Suspected FAS but did not Diagnose	9% (n=22)	56% (n=59)
Never Asking about Alcohol Use During Pregnancy	7% (n=17)	10% (n=10)
Disagree with the Statement that "Discussing the use of alcohol during pregnancy will frighten or anger patients"	79% (n=196)	92% (n=97)
Prepared to deal with patients/parents with alcohol abuse	76% (n=189)	49% (n=51)

3.4.4 Other Descriptive Information

3.4.4.1 Knowledge of Secondary Disabilities Associated with Prenatal Alcohol Exposure

Most physicians also recognized at least some of the other types of problems associated with prenatal alcohol exposure, and these data are illustrated in Table 3.7. Only 9 respondents (9%) correctly identified all the associated features.

Table 3.7: Problems Associated with Prenatal Alcohol Exposure

Problem	Respondents Recognizing the Problem
Delayed development	95% (n=100)
Birth defects/malformations	80% (n=84)
Mental disorders	92% (n=97)
Learning disabilities	97% (n=102)
Lowered IQ/mental retardation	96% (n=101)
Craniofacial deformities	89% (n=94)
Behavioral problems	97% (n=102)
Low birth weight	93% (n=98)
Growth retardation/small for gestational age	92% (n=97)
Premature birth	81% (n=85)
Structural brain damage	68% (n=72)
Spontaneous abortion	64% (n=67)

3.4.4.2 Reporting

Forty-five per cent of respondents believe that there should be mandatory reporting of FAS (n=47) and 44% (n=46) in mandatory reporting of FAE. Unfortunately, most are unaware whether FAS (67%; n=71) and FAE (69%; n=73) are reportable conditions in Saskatchewan. However, 10% (n=10) of respondents reported FAS/FAE to Educational services, 17% (n=18) reported to Social Services, and 7% (n=7) reported to other services. Neither knowledge of FAS nor knowledge of FAE increased the likelihood of reporting the conditions.

3.5 Discussion

This survey was designed to determine the knowledge and attitudes of Saskatchewan's general practitioners toward FAS and FAE. It was hypothesized that respondents would require more education and training to effectively care for affected individuals and their families. And that knowledge has not improved among this cohort over the past decade. Indeed, the data from this survey suggest that, while physicians appear aware of FAS

and FAE, there is still a strong need for increased education, training, and resources for accurate diagnoses and for general practitioners to feel prepared to care for FAS/FAE-affected individuals and their families. A disappointingly low proportion of the survey respondents could correctly identify the sentinel features of Fetal Alcohol Syndrome, suggesting the lack of sufficient knowledge to make an accurate diagnosis. However, the physicians surveyed do recognize that the problem of prenatal alcohol exposure is significant, and many report having either diagnosed or cared for what they believed was an individual affected by prenatal alcohol exposure.

Perhaps the most significant findings of this survey are that 1) Saskatchewan's general practitioners are not knowledgeable about alcohol-related disabilities and their diagnosis, 2) training and resources are necessary to improve their knowledge with respect to FAS and FAE, and 3) FAS-related knowledge of general practitioners in Saskatchewan has not improved since 1992.

The response rate of this survey (28%) was relatively low, but is comparable to the response rates of other recent physician surveys published in the literature. (Field *et al.*, 2002; Jonides *et al.*, 2002) The lower response rate is most likely due to the depth and perceived length of the present survey. A number of respondents commented in the margins that the survey was too lengthy. This particular survey instrument was chosen, however, so that future comparisons can be made with results from an identical survey being currently administered on a National scale by Health Canada.

Results indicate that almost all respondents have at least heard the term FAS and most report having heard of FAS more than 4 years ago. This is not surprising, given that the term FAS was coined in 1973. (Jones and Smith, 1973) However, 3% of the respondents report that they only heard of the term in the last year or two. Since all surveyed were practicing physicians, this suggests that the earliest that these respondents would have heard of the term FAS was during their residency training rather than during medical school. In itself, this suggests that at least some medical training programs are

not providing information about alcohol-related disabilities in their discussions of addictions, teratology, and congenital malformations.

Fewer respondents report having heard of the term FAE and many had heard of it more recently than they report having heard of FAS. This was expected, given that FAE is not a concrete syndrome and is more difficult to define than FAS and, as well, the term "FAE" was coined more recently than the term "FAS".

With respect to FAS and FAE, physicians report that their knowledge was gained mainly through medical journal and books. Perceived knowledge about FAS appeared to surface during training and residency for the majority of the respondents. On the other hand, a low proportion gained FAE knowledge during their training. Together, these data reinforce the fact that accurate information on FAS and FAE must be presented to medical students and reinforced during residency training. Also, a significant proportion of respondents reported that they receive information about FAS and FAE via the mass media, emphasizing the need and the necessity for the dissemination of accurate information through these sources. Unfortunately, mass media-related information is difficult to control and is often incomplete or inaccurate (See Appendix XII).

Overall, the respondents were correct in their estimates of the incidence of FAS with respect to other common childhood afflictions. They correctly believe that the incidence of FAS is higher than that of Down's Syndrome, spina bifida, and cerebral palsy. In fact, FAS is the leading cause of mental retardation in the Western world, (Abel and Sokol, 1987) and many wrote in long-hand on the survey that a common misconception about FAS is that it is of low incidence.

Many respondents could also identify some of the general facts about FAS, but only 15% could identify them all correctly. A different set of physicians could correctly identify the defining features of FAS (11%) as well as the best practice for currently accepted for diagnosis (11%). It was surprising that those who identified all diagnostic

features correctly were not able to correctly identify the general associated characteristics and secondary disabilities. Only 3 (23%) of those knowledgeable of the features of FAS could correctly identify general features and associated disabilities. This suggests that those that appeared knowledgeable about FAS diagnosis may have scored correctly due more to chance than specific knowledge. Support for this notion also comes from examining characteristics and other responses of the knowledgeable physicians. Surprisingly, being knowledgeable about the diagnostic features of FAS was not correlated with any of the other responses that would be expected. For example, being knowledgeable about the diagnostic features of FAS was not correlated with knowledge about FAE, asking pregnant women about alcohol use during pregnancy, having made or reported an FAS diagnosis, feeling more prepared to deal with FAS affected individuals and their families, using an alcohol abuse screening tool, use of a diagnostic schema, giving the advice to pregnant women not to drink during pregnancy, or with place of practice. These findings were not expected, given that knowledge about FAS should, in a logical sense, trigger one to be more apt to ask about alcohol use during pregnancy, increased probability of having made an FAS (or suspected FAS) diagnosis, and feeling more prepared to deal with affected individuals and their families. Together, these data suggest that the survey respondents do not have true knowledge about FAS, even though they correctly answered the question that scored them as knowledgeable.

Survey data suggest that FAS is underdiagnosed in Saskatchewan. A total of only 65 diagnoses of FAS were reported by these survey respondents along with 73 suspected cases and 64 referrals. Based upon an average population of 1,022,040 individuals for the past 5 years in Saskatchewan, however, (Statistics Canada, 2002) it can be calculated that 2044 individuals (0.2% of the population) should be affected by FAS and an additional 8176 (0.8% of the population) by FAE. It must be noted, however, that pediatric specialists were not included in the survey and could account for a larger proportion of diagnostic activities in their practices. This is not a probable explanation, though, given the low number of pediatricians in Saskatchewan (n=41) when compared to the number of family physicians (n=881). In addition, specialists do not tend to have

access to the highest risk populations who live in the more rural communities served by family physicians. It is the family physicians who are more likely the primary care providers to the affected individuals and their families and thus, the responsibility of making accurate FAS diagnoses or offering referral services is often theirs.

Asking pregnant women about alcohol use during pregnancy is an important part of FAS-prevention (by telling a women it is not safe to consume alcohol during pregnancy) and is key for making an alcohol-related diagnosis or referral. Almost 90% of respondents report asking all pregnant women if they are currently drinking alcohol and give the advice to pregnant women that no alcohol is recommended during pregnancy. None report that they tell their patients that alcohol is only dangerous during the first trimester, yet a small proportion do convey that a glass of beer or wine in moderation is okay or do not give specific recommendations to their patients with respect to drinking alcohol during pregnancy. The majority report that there is not enough time to talk to pregnant women about alcohol use before they become pregnant and also say that information on drinking during pregnancy is not available in a useful form, yet they do believe that solid information is available. Almost half of the respondents believe, however, that their patients already have good knowledge about the effects of alcohol use during pregnancy. Thus, it is key to disseminate to physicians the importance of asking about alcohol use during pregnancy, advising pregnant women not to consume alcohol during pregnancy, and to provide them with appropriate information for their patients.

It would be logical to predict that the majority of the diagnoses in Saskatchewan are being made by rural practitioners, given that FAS is anticipated to occur in higher proportions in rural areas. (May *et al.*, 2000) Indeed, the rural practitioners reported on this survey that they diagnose FAS at over twice the rate of the urban practitioners. This reinforces the notion that FAS may occur in higher proportions in the rural areas of Saskatchewan. It could also suggest that urban general practitioners refer their patients to a diagnostic clinic (a clinic is located in Saskatoon) rather than making the diagnosis

themselves, although reported numbers of referrals did not depend upon place of practice.

It is noteworthy that urban practitioners (who appear to be making fewer of the diagnoses) are not more knowledgeable about FAS diagnostic characteristics and procedures than the rural practitioners (who report making more of the diagnoses), suggesting again that diagnostic knowledge is not correlated with diagnostic activity.

Together, these results suggest that Saskatchewan's general practitioners require more education and training to accurately diagnose FAS and to most effectively care for vulnerable pregnant women and affected individuals and their families. The importance of diagnosis to improve outcome is not recognized, since many respondents do not make alcohol-related diagnoses or referrals for diagnosis and ten percent still believe that making a diagnosis will not make a difference. Respondents both knowledgeable and unknowledgeable of the defining features of FAS reported that they felt that they required more training and education in order to feel comfortable making a diagnosis. They do not believe that asking patients about alcohol use during pregnancy will anger them or deter them from seeking treatment. Based upon these findings, these types of questions should be included as part of a standard procedure for family physicians caring for pregnant women and women of childbearing age. The respondents identify CME training as being the most helpful to aid them with diagnosis and telehealth as the least helpful.

There were no statistically significant differences for the physicians' responses to the identification of the cardinal features of FAS and the related secondary characteristics/disabilities to be dependent upon their year of graduation from medical school, although the majority of the knowledgeable graduated between 1974 and 1989. The trend, however, was surprising and disturbing. Since FAS was officially recognized in 1973, (Jones and Smith, 1973; Jones *et al.*, 1973) it is reasonable that those receiving medical training around this time would be more familiar with the syndrome than those receiving training prior to its recognition. However, it was surprising that there was a

tendency for those physicians graduating after 1989 to have *lower* levels of knowledge with respect to FAS, lending support for the requirement of increased medical school and residency training with respect to either childhood disabilities or substance abuse during pregnancy. It is interesting to note that the most recent graduates, although not at all knowledgeable about FAS, report that they feel the most prepared to care for affected individuals. Clearly there is a discrepancy between their perceived preparedness to care for FAS patients and actual knowledge of FAS.

Survey results suggest that knowledge of Saskatchewan general practitioners about FAS has not improved since they were surveyed in 1992. Although there are some similarities between the data collected in this study and that collected 10 years ago, there are some differences in the responses from the general practitioners. Overall, the ability to correctly identify some key features (facies, growth deficits) associated with FAS appears to have diminished slightly with time, yet more appear aware of the CNS deficits. Fewer physicians also report having made an FAS diagnosis than those surveyed in 1990-1991, but more tend to refer their patients for diagnostic services. The most striking difference between the two samples is the 6-fold increase over the past 10 years in the number of physicians who report having suspected a diagnosis of FAS without diagnosing it. This is obviously not related to increased awareness, since this group was not more aware of the diagnostic features associated with FAS than the previous group surveyed. These physicians, however, may be more aware of *some* of the associated features – enough to make them suspect FAS. Disturbingly fewer physicians in 2002 felt prepared to deal with patients/parents with problems related to alcohol abuse, but slightly more ask about alcohol use during pregnancy. A higher proportion also disagreed with the statement that “discussing the use of alcohol during pregnancy will frighten or anger patients”. This could be due the perception of a changing culture/attitude toward drinking alcohol, in general.

Finally, the physicians surveyed this year report the multi-media as a slightly increased source of information regarding FAS as well as parents and patients (who probably get their information from the media as well). This is understandable, given the amount of

media attention that FAS and FAE have generated lately. In Saskatchewan, posters, pamphlets, and public service announcements are sponsored by the Saskatchewan Institute on Prevention of Handicaps and disseminated to the general public as well as to physicians.

One caveat of the survey instrument is that it did not allow respondents to identify where medical school/residency training took place. There was much ethnic variation among the physicians who were asked to respond and it is possible that many received their medical school/residency training outside Saskatchewan and/or Canada. Thus, generalized statements cannot be made with respect to the amount of training focused on FAS/FAE the respondents received in the province of Saskatchewan's or in Canadian medical schools.

Another caveat is the stringency with which diagnostic knowledge was determined. Since the survey was designed to determine why physicians are not diagnosing FAS in Saskatchewan, and diagnosis depends directly upon knowledge of the cardinal features of FAS, the physician must be able to correctly identify all sentinel features of FAS to be able to make a diagnosis (and to be deemed as knowledgeable). By relaxing the stringency (i.e., 4 of 6 correct responses would score one as knowledgeable), more respondents would have become "knowledgeable" and significant correlations of knowledge with other variables may have been obtained. However, this would not be an accurate measure of diagnostic knowledge, since those truly knowledgeable about FAS diagnoses would have no difficulty in identifying the cardinal features.

With such a small sample size, the power of the statistical tests is not strong and thus, definite conclusions cannot be determined, nor should the data be generalized to the population of health practitioners (or even family physicians) in Saskatchewan.

Finally, the survey response rate, although characteristic of the physician population, was relatively low and therefore should not be generalized to other populations. Because of the anonymity of the surveys, demographical distribution of the respondents

could not be determined and thus, the sample may not be the ideal representation of the province. Possibly, the non-responders were less knowledgeable about the survey questions and were less motivated to respond.

In conclusion, these data suggest that Saskatchewan's general practitioners are not knowledgeable about alcohol-related disabilities, that more information and training is required for physicians to feel comfortable recognizing and diagnosing FAS and FAE as well as for them to be prepared to care for pregnant women in the area of alcohol abuse and individuals and their families affected by prenatal exposure to alcohol. Knowledge has not improved over the past decade. The lack of knowledge is of concern since many unknowledgeable physicians report that they feel prepared to care for FAS-affected individuals and their families and they also report that they indeed diagnose FAS. Thus, the data emphasize the need for training programs targeted to medical students, residents, and practicing general practitioners around issues related to FAS and its associated secondary disabilities. Finally, because of the small numbers of diagnoses and suspect diagnoses being made by family physicians, even though they are the primary care providers for most of Saskatchewan, data suggest that FAS and FAE are still clearly under-diagnosed in Saskatchewan.

4.0 Conclusion

The initial aim of this proposal was to determine the economic cost of FAS and FAE to Saskatchewan by determining the services utilized and the extent of their utilization by affected individuals and their families. However, the data required was unavailable because FAS/FAE affected individuals are not labeled as affected in provincial databases. It was possible that affected individuals are not diagnosed. Diagnosis is key to receiving access to special services (i.e., interventions) that will improve outcome for FAS-affected individuals and their families and communities. Thus, a physician survey was developed to determine if Saskatchewan's general practitioners feel comfortable caring for pregnant women in the area of alcohol abuse during pregnancy and have sufficient training and education to accurately diagnose FAS and other alcohol-related disabilities or to screen for alcohol-related disabilities and make a referral for diagnosis.

4.1 Economic Analysis

Some of the economic costs of FAS and FAE to Saskatchewan were estimated in this manuscript. Costs associated with justice, education, social services, and health were estimated to total \$44 million/year (please refer to Figure 4.1 for a breakdown of costs).

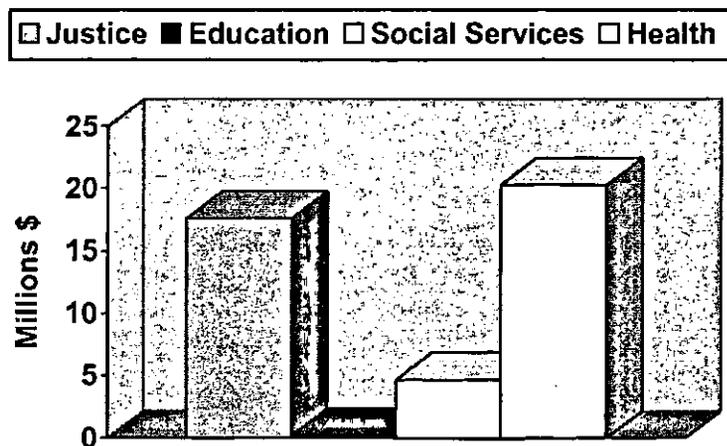


Figure 4.1: Total Estimated Costs of FAS/FAE to Justice, Education, Social Services, and Health in Saskatchewan. Costs of FAS/FAE to Saskatchewan Justice, Education, Social Services, and Health are estimated to be \$17.6 million/year, \$0.245 million/year, \$5.88 million/year, and \$20.3 million/year, respectively. The total cost of prenatal alcohol exposure to Saskatchewan Justice, Health, Education, and Social Services can be estimated as \$44 million/year.

The literature suggests that early intervention programs can mitigate the onset of secondary disabilities associated with prenatal alcohol exposure (Streissguth *et al.*, 1997; Streissguth, 1997; Streissguth and Kanter, 1997; Astley and Clarren, 1999), improving the outcome of affected individuals. Concomitant with improved outcome is a decreased need for services and decreased utilization of services, resulting in an overall decrease in associated costs to the province of Saskatchewan. In fact, it has been reported that the cost of raising a child with FAS would be approximately 30 times the cost of preventing FAS in the child. (Astley *et al.*, 2000)

This is especially important in Saskatchewan, where provincial funding for intervention programs is low despite the fact that the prevalence of FAS and FAE is anticipated to increase significantly (see Table 2.3, page 49). Showing funding agencies the short and long-run cost-savings associated with the investment of monies into developing appropriate intervention programs (please refer to Table 7 for a simple example) may

prove to be an effective way of ultimately improving the outcome for FAS-affected individuals and their families. By approaching government to fund the type of program that would give them the most significant return on their investment (i.e., by decreasing long-run costs associated with Justice), both the economy of Saskatchewan as well as the quality of life for the residents would be improved.

By determining the services utilized by FAS/FAE affected individuals and their families and the extent of their utilization, associated costs can be determined. With the development of targeted programs for justice, health, social services, and education, effects on outcome (measured by changes in services utilization rates) can be measured as well as accurate cost-savings. However, these types of investigations will only be possible when FAS/FAE cases are identified in provincial databases. This, of course, depends on accurate diagnosis and diligent reporting.

4.2 Prevalence and Incidence Data

Determining economic costs associated with alcohol abuse and Fetal Alcohol Syndrome are impossible without knowing how many individuals are affected by prenatal alcohol exposure in Saskatchewan. Information on the incidence and prevalence is also directly related to accurate diagnosis of the affected individuals and reporting of the cases into a pan-provincial database

4.3 The Physician Survey

Physicians often provide the primary medical care for pregnant females and thus have an important role to play in the prevention and education about FAS. In Saskatchewan, most of the population is served by general practitioners and thus, the responsibility of diagnosis and caring for individuals and families affected by prenatal alcohol exposure lies with these practitioners. However, there is a significant amount of disparity among these physicians with respect to knowledge, attitudes, practices, and educational needs regarding FAS.

The physician survey was designed to obtain information from Saskatchewan general practitioners regarding their current level of knowledge and attitudes toward FAS and FAE to determine whether FAS and FAE are being diagnosed by general practitioners and if not, to provide possible explanations. Results suggest that more education and training is required with respect to FAS and its related disabilities and general practitioners tend not to report diagnosed or suspect cases to a provincial registry (in fact, such a registry does not exist, but survey respondents identified that they would like one to be developed). By comparing data to the Nanson survey administered in 1992 (Nanson *et al.*, 1995), it was determined that knowledge of Saskatchewan's general practitioners about FAS has not improved over the past decade. Targeted training and education programs are required to enable physicians to identify alcohol-related disorders and disabilities and to gather and disseminate appropriate information to make accurate referrals and diagnoses.

The results of this survey will be important to use to identify the requirements for and the type of policy planning and educational initiatives for general practitioners with respect to FAS and FAE.

4.4 Summary

FAS and FAE are underdiagnosed and physicians do not appear to be comfortable making diagnoses. They report a need for increased training and education with respect to identification and understanding of the disabilities. Standardizing the diagnostic procedure, as well as making it more objective, is one mechanism that will assist physicians in making accurate diagnoses. The long-term effects will be the development of more effective programs for affected children and their communities as well as a more complete understanding of the prevalence and economic costs of FAS and FAE.

5.0 Policy Recommendations

Before we can reduce the incidence of fetal alcohol syndrome and its effects, we must determine what the incidence is and what the effects are. We must understand both the primary and the secondary disabilities associated with FAS and FAE, and we must learn which types of programs reduce these effects and provide the best long-term outcome for affected children and their families. Significant costs are borne by society because of high utilization rates of provincially-funded services by individuals affected by prenatal alcohol exposure and their families. Thus, a number of general and specific policy recommendations can be made according to the data of this proposal.

5.1 Standardized FAS/FAE Diagnostic Guidelines

In order to determine outcome measures such as incidence/prevalence, upon which hinge further downstream variables such as economic costs and effective intervention program development, FAS and FAE must be recognized, diagnosed, and documented. The most significant responsibility lies with the physician who tends to the mother throughout pregnancy and/or treats the child after birth.

There is evidence that FAS and FAE are under-diagnosed in Saskatchewan and across Canada, in general. Survey data suggest that guidelines for diagnosis would be helpful for Saskatchewan general practitioners to make accurate and objective diagnoses. Such guidelines should be developed by clinicians from diagnostic centres in Canada and guidelines should be implemented on a National scale.

5.2 *Linking Family Support Services and Intervention Programs to Diagnosis*

If a positive diagnosis is to benefit the affected individual and their families, an alcohol-related diagnosis must be linked to family support services and intervention programs. Affected families and communities do not want to have their members labeled with a type of disability if it will not provide a positive outcome. (Merasty, 2002)

Programs need not be complicated and costly. Affected children will benefit from any type of program if the alternative is no program. Even a general awareness by affected individuals and those around them of FAS and FAE and the associated strengths and limitations can be helpful, improve outcome, and lessen feelings of blame and frustration in the long run.

5.3 *Standardized Training and Education for Health Care Professionals*

Survey data suggest that general practitioners in Saskatchewan require additional training and education to feel more prepared to care for pregnant women in the area of alcohol abuse as well as to care for individuals and their families affected by prenatal alcohol exposure. Training and education programs should be developed that are geared toward the identified specific needs of physicians and should be standardized across the country with respect to content and delivery. Their objectives should be to improve professional preparedness to care for care for alcohol dependent/abusing pregnant women and individuals affected by prenatal alcohol exposure as well as to increase to understanding of the long term secondary disabilities associated with prenatal alcohol exposure.

It must be recognized that there are clear differences in the demographic composition of Canada's provinces, territories, and communities and this adds a layer of complexity when designing and developing nationwide programs for education and training. This is because different provinces/communities may have different requirements for education and training that may depend on the state of current FAS programs in their province (e.g., Saskatchewan physicians would be expected to be more knowledgeable than

physicians from the other prairie provinces because of the concentrated efforts of the Saskatchewan Institute on Prevention of Handicaps with respect to FAS awareness and prevention). Thus, there is a requirement for training and educational programs to be *adaptable* to the needs of the physicians, based upon factors including their perceived requirements and the way in which their patients will be most responsive and receptive to the information (i.e., there must be a component that is sensitive to cultural practices). All training programs should be approved for continuing medical education credits for participants.

Based upon survey data, all training programs should include:

- Screening women at risk for alcohol use during pregnancy

All women who are seen by primary care physicians, midwives, or nurse practitioners should be asked about their drinking habits, especially if they are pregnant. This should be done in a respectful manner and dependent drinkers should be asked to abstain for the remainder of their pregnancy as well as be referred for treatment, whenever possible.

Effective approaches of identifying high risk women and gearing them toward prevention programs would eliminate most of the existing FAS problem, since these women account for the majority of the FAS cases. (Institute on Alcohol, Alcoholism, and Alcoholics, 2000) However, gathering data on these women is problematic because they do not reliably appear for prenatal care and tend to be untruthful about their drinking and lifestyle habits. Thus, there is a need for information to develop effective targeting strategies for prevention (e.g., How can the right message reach the right people?), referral patterns (e.g., How will we ensure that the right people are referred to the right programs?), and intervention/prevention components (e.g., Which types of programs work best for different types of people?). Culturally appropriate approaches to screening must also be determined and developed for use in different populations by different types of health professionals.

- Screening for prenatal alcohol exposure

Because a diagnosis of FAS/FAE is usually only made by trained professionals based upon systems of referrals, screening of potentially-affected individuals is of significant concern. At present, there are no effective screening tools that have been deemed sensitive and reliable enough and, as a result, none have been officially validated for use. However, individuals can be trained to recognize the hallmark of features and characteristics of FAS and FAE (after they have been clearly defined and delineated).

One possibility for a screening tool more specific to FAS could involve taking anthropometric measurements for facial deformities, setting baselines based upon parental measurements and accounting for racial differences.

- Importance of gathering maternal history data on alcohol consumption during pregnancy

It should be emphasized that general practitioners can play a critical role in the prevention of alcohol-related disabilities by advising pregnant women to abstain from alcohol use during pregnancy. Also, FAS prevalence is still unknown in the general population, and it is feasible that children are misdiagnosed (i.e. ADHD) when questions regarding prenatal consumption of alcohol are not addressed. Misdiagnosis can result in inappropriate treatment and poor outcomes for individuals and families.

5.4 Telemedicine/Telediagnosis

Educating physicians about the utility of telehealth and telediagnosis is recommended. Many provinces are struggling to provide FAS diagnostic services, since the diagnosis is complicated (at the present time, also rather subjective in nature) and requires the specialized knowledge of several different types of health care professionals. Telemedicine and telediagnosis may be a solution and is presently utilized by Manitoba's Thompson and Winnipeg FAS clinics.

Telemedicine involves using communication technologies (internet, videoconferencing) to access patient information over a long-distance. Telediagnosis is making diagnoses using telemedicine. Telediagnosis could be especially useful in remote or rural settings, in settings without access to physician services, or in instances when access to specialized medical opinions is scarce.

Telemedicine can also offer practical and economical solutions to modern problems of health care that plague the field of FAS and FAE. There is a lack of trained diagnostic professionals and lack of access to a full multi-disciplinary diagnostic team. In many cases, potential patients do not have access to someone trained in diagnosis and it is not economical to provide in-person access in other situations. Thus, rather than having the specialists or the patients traveling around, use of telediagnosis will save time and money. Such activities will also help to reduce the isolation of rural health care professionals, as well as provide an opportunity for continuous medical education and training with respect to FAS and FAE.

5.5 Registries and Surveillance

Following diagnosis of a disability related to prenatal alcohol exposure, the case should be reported to a provincial registry database. In this manner, different sectors (i.e., social services, education, justice, health) could have access to this information if required. With reporting to a registry of cases, surveillance to determine incidence and prevalence will be possible.

5.6 Conclusion

Clearly, FAS, FAE and its effects on individuals and society are complex. Although recognized as a problem since 1973, there is still a long way to go in terms of improving the lives of affected individuals and those around them.

Without knowing how many individuals are affected prenatally by alcohol, downstream impact is impossible to determine. Thus, lack of incidence/prevalence data is a

significant hindrance to obtaining other types of data, including demographics, economic impact, and the need for the development of intervention programs. As well, it makes it difficult to lobby governments and other funding organizations for monies to be used for FAS/FAE programs, including prevention, awareness, education, training, and intervention.

Appendix I: Costs of FAS/FAE to Youth Justice in Saskatchewan

Year	Number in custody day at once	Cost/kid/ day	Total Cost/ Year	% FAS	Total Cost of FAS	%FAE	Total Cost of FAE	Total Cost of Prenatal Alcohol Exposure
2000	442	\$85	\$13,713,050	0.01	\$137,130	0.223	\$3,058,010	\$3,195,140

Appendix II: Costs of FAS/FAE to Adult Justice in Saskatchewan

Factor of adult vs youth			
	4.5 FAE costs	FAS costs	Total Costs of Prenatal Alcohol Exposure
	\$13,761,046	\$617,087	\$14,378,133
Adult and Youth Justice			
<i>Total Costs for Adult and Youth Justice</i>	<i>\$16,819,056</i>	<i>\$754,218</i>	<i>\$17,573,274</i>

Appendix III: Costs of FAS/FAE to Social Services in Saskatchewan

Social Services						
Saskatchewan Social Services Budget	FAS Prevalence Rate	FAS Costs	FAE Prevalence Rate	FAE Costs	Total Costs of Prenatal Alcohol Exposure	
\$588,000,000	0.002	\$1,176,000	0.008	\$4,704,000	\$5,880,000	

Appendix IV: Costs of FAS/FAE to Education in Saskatchewan

Special Ed costs/child	Special Ed Costs	Incidence of FAS	Cost of FAS	Incidence of FAE	Costs of FAE	Costs of Prenatal Alcohol Exposure
	\$6,000	0.002		0.008		
District 1	\$3,840,000		\$7680		\$30,720	\$38,400
District 2	\$0		\$0		\$0	\$0
District 3	\$54,000		\$108		\$432	\$540
District 4	\$6,000		\$12		\$48	\$60
District 5	\$16,368,000		\$32,736		\$130,944	\$163,680
District 6	\$3,162,000		\$6324		\$25,296	\$31,620
District 7	\$360,000		\$720		\$2880	\$3600
District 8	\$690,000		\$1380		\$5520	\$6900
Total	\$24,480,000		\$48,960		\$195,840	\$244,800

Appendix V: Costs
 Appendix V: Costs

Appendix V: Costs of FAS/FAE to Health in Saskatchewan

Saskatchewan Health 'Budget	FAS Rate	FAS Costs	FAE Rate	FAE Costs	Total Costs of Prenatal Alcohol Exposure
\$2,031,000,000	0.002	\$4,062,000	0.008	\$16,248,000	\$20,310,000
Accidents/ER					
\$23,296,000	0.002	\$46592	0.008	\$186,368	\$232,960
Costs					
<i>Cost to ER</i>		\$90			
<i>Family Dr visit</i>		\$21			
<i>Alcohol Rehab (/yr)</i>		\$2,415			
<i>Childbirth</i>		\$2,560			

Appendix VI: Total Costs of FAS/FAE to Saskatchewan

Total Costs			
	FAS	FAE	Total
Justice	\$754,218	\$16,819,056	\$17,573,274
Education	\$48,960	\$195,840	\$244,800
Social Services	\$11,760,000	\$47,040,000	\$5,880,000
Health	\$40,620,000	\$162,480,000	\$20,310,000
Total	\$6,041,178	\$37,790,640	\$44,008,074

Appendix VII: Cost Projections for FAS/FAE to Saskatchewan

General information:

Saskatchewan population (2001)	1,015,800	
FAS prevalence	0.002	0.01
FAE prevalence	0.008	0.233
Aboriginal Population FAS Rate	0.88	
Aboriginal population growth rate	1.02	
Growth rate of FAS	1.0172	

Population and Incidence Projections:

Incidences	2001	2002	2003	2004	2005	2006	2007
FAS	2031	2066	2102	2138	2175	2212	2250
FAE	8126	8266	8408	8553	8700	8849	9001
Total	10158	10332	10510	10691	10875	11062	11252
Total in Aboriginal population	8939	9117	9300	9486	9675	9869	10066

Incidences	2008	2009	2010	2011	2012	2013	2014
FAS	2289	2328	2368	2409	2450	2493	2535
FAE	9156	9314	9474	9637	9803	9971	10143
Total	11446	11642	11843	12046	12254	12464	12679
Total in Aboriginal population	10268	10473	10683	10896	11114	11336	11563

Incidences	2015	2016	2017	2018	2019	2020	2021
FAS	2579	2623	2668	2714	2761	2809	2857
FAE	10317	10495	10675	10859	11046	11236	11429
Total	12897	13119	13344	13574	13807	14045	14286
Total in Aboriginal population	11794	12030	12271	12516	12767	13022	13282

Cost Projections Based on Population Projections:

Youth Offender Costs (\$ millions)	2001	2002	2003	2004	2005	2006	2007
FAS	\$0.14	\$0.14	\$0.14	\$0.15	\$0.15	\$0.15	\$0.15
FAE	\$3.06	\$3.12	\$3.18	\$3.25	\$3.31	\$3.38	\$3.44
Total	\$3.20	\$3.26	\$3.32	\$3.39	\$3.46	\$3.53	\$3.60

Adult Corrections Costs (\$ millions)	2001	2002	2003	2004	2005	2006	2007
FAS	\$0.62	\$0.63	\$0.64	\$0.65	\$0.67	\$0.68	\$0.69
FAE	\$13.80	\$14.08	\$14.36	\$14.64	\$14.94	\$15.24	\$15.54
Total	\$14.42	\$14.71	\$15.00	\$15.30	\$15.61	\$15.92	\$16.24

Total FAS							
Total FAE							
Total Corrections costs (\$ millions)	\$17.61	\$17.96	\$18.32	\$18.69	\$19.06	\$19.44	\$19.83

Social Services Costs (\$ millions)	2001	2002	2003	2004	2005	2006	2007
FAS	\$1.20	\$1.24	\$1.29	\$1.33	\$1.38	\$1.43	\$1.48
FAE	\$4.70	\$4.85	\$5.01	\$5.17	\$5.34	\$5.51	\$5.69
Total	\$5.90	\$6.09	\$6.30	\$6.50	\$6.72	\$6.94	\$7.17

Education Costs (\$ millions)	2001	2002	2003	2004	2005	2006	2007
FAS	\$0.05	\$0.05	\$0.05	\$0.05	\$0.06	\$0.06	\$0.06
FAE	\$0.21	\$0.22	\$0.22	\$0.23	\$0.24	\$0.25	\$0.25
Total	\$0.26	\$0.27	\$0.28	\$0.29	\$0.29	\$0.30	\$0.31

Health Costs (\$ millions)	2001	2002	2003	2004	2005	2006	2007
FAS	\$4.06	\$4.20	\$4.35	\$4.51	\$4.66	\$4.83	\$5.00
FAE	\$16.25	\$16.78	\$17.32	\$17.88	\$18.46	\$19.06	\$19.68
Total	\$20.31	\$20.98	\$21.67	\$22.39	\$23.13	\$23.89	\$24.68

TOTAL COSTS (\$ millions)	2001	2002	2003	2004	2005	2006	2007
FAS	\$6.06	\$6.28	\$6.50	\$6.73	\$6.97	\$7.21	\$7.47
FAE	\$34.96	\$36.09	\$37.27	\$38.48	\$39.72	\$41.01	\$42.35
TOTAL (\$ millions)	\$41.02	\$42.37	\$43.76	\$45.20	\$46.69	\$48.23	\$49.81

Youth Offender Costs (\$ millions)	2008	2009	2010	2011	2012	2013	2014
FAS	\$0.16	\$0.16	\$0.16	\$0.17	\$0.17	\$0.17	\$0.18
FAE	\$3.51	\$3.58	\$3.65	\$3.73	\$3.80	\$3.88	\$3.96
Total	\$3.67	\$3.74	\$3.82	\$3.89	\$3.97	\$4.05	\$4.13

Adult Corrections Costs (\$ millions)	2008	2009	2010	2011	2012	2013	2014
FAS	\$0.71	\$0.72	\$0.74	\$0.75	\$0.77	\$0.78	\$0.80
FAE	\$15.85	\$16.17	\$16.49	\$16.82	\$17.16	\$17.50	\$17.85
Total	\$16.56	\$16.89	\$17.23	\$17.57	\$17.93	\$18.28	\$18.65

Total FAS							
Total FAE							
Total Corrections costs (\$ millions)	20.23	20.63	21.05	21.47	21.90	22.34	22.78

Social Services Costs (\$ millions)	2008	2009	2010	2011	2012	2013	2014
FAS	\$1.53	\$1.58	\$1.64	\$1.70	\$1.76	\$1.82	\$1.88
FAE	\$5.88	\$6.07	\$6.27	\$6.47	\$6.68	\$6.90	\$7.12
Total	\$7.41	\$7.65	\$7.91	\$8.17	\$8.44	\$8.72	\$9.00

Education Costs (\$ millions)	2008	2009	2010	2011	2012	2013	2014
FAS	\$0.06	\$0.06	\$0.07	\$0.07	\$0.07	\$0.07	\$0.08
FAE	\$0.26	\$0.27	\$0.28	\$0.29	\$0.30	\$0.31	\$0.32
Total	\$0.33	\$0.34	\$0.35	\$0.36	\$0.37	\$0.38	\$0.40

Health Costs (\$ millions)	2008	2009	2010	2011	2012	2013	2014
FAS	\$5.18	\$5.36	\$5.55	\$5.74	\$5.95	\$6.16	\$6.37
FAE	\$20.32	\$20.98	\$21.66	\$22.37	\$23.09	\$23.84	\$24.61
Total	\$25.50	\$26.34	\$27.21	\$28.11	\$29.04	\$30.00	\$30.99

TOTAL COSTS (\$ millions)	2008	2009	2010	2011	2012	2013	2014
FAS	\$7.73	\$8.00	\$8.28	\$8.58	\$8.88	\$9.19	\$9.52
FAE	\$43.72	\$45.14	\$46.60	\$48.12	\$49.68	\$51.29	\$52.96
TOTAL (\$ millions)	\$51.45	\$53.14	\$54.89	\$56.69	\$58.56	\$60.48	\$62.47

Youth Offender Costs (\$ millions)	2015	2016	2017	2018	2019	2020	2021	2022
FAS	\$0.18	\$0.18	\$0.19	\$0.19	\$0.20	\$0.20	\$0.20	\$0.21
FAE	\$4.03	\$4.12	\$4.20	\$4.28	\$4.37	\$4.45	\$4.54	\$4.63
Total	\$4.22	\$4.30	\$4.39	\$4.47	\$4.56	\$4.65	\$4.75	\$4.84

Adult Corrections Costs (\$ millions)	2015	2016	2017	2018	2019	2020	2021	2022
FAS	\$0.81	\$0.83	\$0.85	\$0.86	\$0.88	\$0.90	\$0.92	\$0.94
FAE	\$18.21	\$18.57	\$18.94	\$19.32	\$19.71	\$20.10	\$20.51	\$20.92
Total	\$19.02	\$19.40	\$19.79	\$20.19	\$20.59	\$21.00	\$21.42	\$21.85

Total FAS							1.12	
Total FAE							25.05	
Total Corrections costs (\$ millions)	23.24	23.70	24.18	24.66	25.15	25.66	26.17	26.70

Social Services Costs (\$ millions)	2015	2016	2017	2018	2019	2020	2021	2022
FAS	\$1.95	\$2.02	\$2.09	\$2.16	\$2.24	\$2.32	\$2.40	\$2.49
FAE	\$7.35	\$7.59	\$7.84	\$8.09	\$8.35	\$8.62	\$8.90	\$9.19
Total	\$9.30	\$9.61	\$9.93	\$10.25	\$10.59	\$10.94	\$11.30	\$11.68

Education Costs (\$ millions)	2015	2016	2017	2018	2019	2020	2021	2022
FAS	\$0.08	\$0.08	\$0.09	\$0.09	\$0.09	\$0.09	\$0.10	\$0.10
FAE	\$0.33	\$0.34	\$0.35	\$0.36	\$0.37	\$0.39	\$0.40	\$0.41
Total	\$0.41	\$0.42	\$0.44	\$0.45	\$0.46	\$0.48	\$0.50	\$0.51

Health Costs (\$ millions)	2015	2016	2017	2018	2019	2020	2021	2022
FAS	\$6.60	\$6.83	\$7.07	\$7.32	\$7.58	\$7.85	\$8.13	\$8.41
FAE	\$25.41	\$26.24	\$27.09	\$27.97	\$28.88	\$29.81	\$30.78	\$31.78
Total	\$32.01	\$33.07	\$34.16	\$35.29	\$36.46	\$37.66	\$38.91	\$40.19

TOTAL COSTS (\$ millions)	2015	2016	2017	2018	2019	2020	2021	2022
FAS	\$9.85	\$10.20	\$10.56	\$10.93	\$11.32	\$11.72	\$12.13	\$12.56
FAE	\$54.67	\$56.45	\$58.28	\$60.17	\$62.13	\$64.14	\$66.22	\$68.37
TOTAL (\$ millions)	\$64.53	\$66.65	\$68.84	\$71.11	\$73.45	\$75.86	\$78.36	\$80.94

millions) \$64.53 \$66.65
 millions) \$64.53 \$66.65

Appendix VIII: Physician Survey



Fetal Alcohol Syndrome Survey for Health Professionals

Part A (General knowledge and attitudes)

In recent years there has been increased investigation about the effects of alcohol consumption during pregnancy and the potential for subsequent morbidity and mortality among offspring. Experimental findings have been the main focus. Clinical aspects have received less attention. It would be helpful to know what information has reached you, whether it has been useful, and how it could be improved.

Fetal Alcohol Syndrome (FAS)

1.1 When did you first hear of FAS? (Please select one answer only.)

- In the last year or two
- Three to four years ago
- More than four years ago
- Never

1.2 From what sources have you gained knowledge about FAS? (Please select all that apply.)

- Mass Media
- Parents/patients
- Colleagues
- CME seminars, rounds
- Medical journals, books
- Medical school, residency, fellowship
- Other (please specify)

2. In your opinion, is the incidence of FAS in Canada higher, equivalent, or lower than the incidence of each of the following?

- | | Higher | Equivalent | Lower | Don't know |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 2.1 Down's Syndrome | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2.2 Spina Bifida | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2.3 Asthma | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2.4 Cerebral Palsy | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2.5 Juvenile Diabetes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

3. Please indicate your opinion on the following statements:

- | | Strongly agree | Agree | Disagree | Strongly disagree | Undecided |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 3.1 FAS is an identifiable syndrome. | <input type="radio"/> |
| 3.2 Alcohol's effect on fetal development remains unclear. | <input type="radio"/> |
| 3.3 It is the physician's role to manage problems in the area of alcohol use. | <input type="radio"/> |
| 3.4 It is the Midwife's role to manage problems in the area of alcohol use. | <input type="radio"/> |
| 3.5 FAS occurs in all strata of society. | <input type="radio"/> |
| 3.6 FAS occurs at similar rates among all cultures and ethnic groups. | <input type="radio"/> |
| 3.7 The drinking patterns of pregnant women are substantially influenced by the drinking patterns of their male partners. | <input type="radio"/> |
| 3.8 Discussing alcohol use during pregnancy will frighten or anger patients. | <input type="radio"/> |
| 3.9 Discussing the use of alcohol during pregnancy will deter women from continuing and/or seeking treatment. | <input type="radio"/> |
| 3.10 Making a diagnosis of FAS does not change anything for the child. | <input type="radio"/> |
| 3.11 Prenatal alcohol exposure is a significant risk factor for permanent brain damage. | <input type="radio"/> |

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Fetal Alcohol Effects (FAE) or Alcohol-Related Neurodevelopmental Defects (ARND)

4.1 When did you first hear of FAE or ARND? (Please select one answer only.)

- In the last year or two
- Three to four years ago
- More than four years ago
- Never

4.2 From what sources have you gained knowledge about FAE or ARND? (Please select all that apply.)

- Mass Media
- Parents/patients
- Colleagues
- CME seminars, rounds
- Medical journals, books
- Medical school, residency, fellowship
- Other (please specify)

5. Please indicate your opinion on the following statements. The term FAE ...

- | | Agree | Disagree | Don't know |
|---|-----------------------|-----------------------|-----------------------|
| 5.1 is used if the child is too young to make a firm diagnosis of FAS. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.2 is used when birth defects from prenatal alcohol exposure diminish over time. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.3 is used to denote a less severe form of FAS. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.4 is used if there is no obvious facial dysmorphology. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.5 is used if the child shows only partial expression of FAS. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.6 is used if there are no IQ deficits. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.7 is used if the child has birth defects but maternal alcohol use history is unclear. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.8 is used if the child demonstrates only behavioural components of syndrome. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5.9 results in better long term social outcomes than if the term FAS is used. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Prenatal Alcohol Exposure

6. Do you consider the following types of problems to be outcomes of prenatal alcohol exposure?

- | | Yes | No | Don't know |
|--|-----------------------|-----------------------|-----------------------|
| 6.1 Infantile withdrawal symptoms | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.2 Delayed development | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.3 Birth defects/malformations | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.4 Mental disorders | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.5 Learning disabilities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.6 Lowered IQ/retardation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.7 Craniofacial deformities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.8 Behavioural problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.9 Low birth weight | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.10 Growth retardation, small for gestational age | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.11 Premature birth (<37 weeks) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.12 Above average birth weight (>4000 grams) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.13 Seizures | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.14 Vision problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.15 Structural brain damage | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6.16 Spontaneous abortion | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



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7. In your opinion, are the following specific conditions now considered to be under the spectrum of disorders associated with prenatal alcohol exposure?

	Yes	No	Don't know
7.1 Fetal Alcohol Syndrome (FAS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.2 Sentinel Birth Defect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.3 Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.4 Neurological Impairment, Organic Brain Damage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.5 Fetal Alcohol Effects (FAE)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.6 Alcohol Related Neurodevelopment Defects (ARND)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.7 Diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.8 Alcohol Related Birth Defects (ARBD)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.9 Hyperactivity disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.10 Failure to thrive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.11 Bronchopulmonary dysplasia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.12 Necrotizing Enterocolitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Alcohol Use

8. Patients, both men and women, are often told to drink only "in moderation."

8.1 Do you agree with this practice? Yes No

8.2 What is your definition of a moderate level of alcohol consumption for non-pregnant women?

8.2a Average number of drinks per occasion:

8.2b Average number of drinking occasions per week:

9.1 How prepared do you feel to care for the following groups of clients in the area of alcohol abuse or dependency?

	Very prepared	Prepared	Unprepared	Very unprepared	Do not care for
9.1.1 Pregnant women	<input type="radio"/>				
9.1.2 Birth mothers	<input type="radio"/>				
9.1.3 Foster parents	<input type="radio"/>				
9.1.4 Affected individuals	<input type="radio"/>				

9.2 How prepared do you feel to access resources for the following groups of clients in the area of alcohol abuse or dependency?

	Very prepared	Prepared	Unprepared	Very unprepared	Do not care for
9.2.1 Pregnant women	<input type="radio"/>				
9.2.2 Birth mothers	<input type="radio"/>				
9.2.3 Foster parents	<input type="radio"/>				
9.2.4 Affected individuals	<input type="radio"/>				

10. Please rate how helpful the following kinds of materials or supports would be to you in your clinical practice.

	Very helpful	Somewhat helpful	Not very helpful	Not at all helpful
10.1 Literature on the impact of alcohol use during pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.2 Pregnancy history checklists including terms on alcohol use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.3 Materials or training on FAS/FAE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.4 Training in addiction counselling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.5 Registry of specialists available for consultation about FAS/FAE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.6 Referral resources for women of childbearing age with alcohol problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.7 Clinical Practice Guidelines for diagnosis of FAS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.8 Assistance with the diagnosis of FAS/FAE through Telemedicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.9 Access to information about FAS/FAE through Telemedicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.10 Internet resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.11 Other (please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Part B
(Prevention issues)

Women receive different types of information about how to achieve and maintain a healthy pregnancy. Please consider your own practice when answering the following questions.

Non-Pregnant Women

11.1 Do you treat non-pregnant women of childbearing age? Yes No

If "No," please proceed to Question 15.

11.2 How often do you discuss the following with...
...all women of childbearing age? ...those in a likely position to conceive?

	Frequently	Sometimes	Rarely	Never	Frequently	Sometimes	Rarely	Never
11.2.1 role of folic acid in decreasing NTD	<input type="radio"/>							
11.2.2 risks of smoking during pregnancy	<input type="radio"/>							
11.2.3 risks of alcohol during pregnancy	<input type="radio"/>							
11.2.4 risks of drug use during pregnancy	<input type="radio"/>							
11.2.5 nutrition	<input type="radio"/>							
11.2.6 workplace stress	<input type="radio"/>							
11.2.7 mental health	<input type="radio"/>							
11.2.8 weight management	<input type="radio"/>							
11.2.9 partner's use of drugs and alcohol	<input type="radio"/>							
11.2.10 depression	<input type="radio"/>							
11.2.11 birth control	<input type="radio"/>							
11.2.12 Pap testing	<input type="radio"/>							
11.2.13 sexual history	<input type="radio"/>							

12. How routinely do you obtain a detailed history about the following from...
...all women of childbearing age? ...those in a likely position to conceive?

	Frequently	Sometimes	Rarely	Never	Frequently	Sometimes	Rarely	Never
12.1 sexual abuse	<input type="radio"/>							
12.2 emotional abuse	<input type="radio"/>							
12.3 alcohol use	<input type="radio"/>							
12.4 personal history of addictions	<input type="radio"/>							
12.5 family history of alcohol misuse	<input type="radio"/>							



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13. How routinely do you provide written information about prenatal alcohol exposure to...

13.1 ...all women of childbearing age?

- Frequently, Sometimes, Rarely, Never

13.2 ...those in a likely position to conceive?

- Frequently, Sometimes, Rarely, Never

14. There are many reasons why health professionals may not be talking to women about alcohol use before they become pregnant.

Indicate whether the following apply to you.

- 14.1 There is not enough time in an office visit to talk to women about these topics.
14.2 There are other sources of information on alcohol use to which you refer women.
14.3 There is not enough solid information available about alcohol use.
14.4 Many of your clients are not interested in discussing alcohol use.
14.5 Many of your clients already have a good knowledge about alcohol use.
14.6 Information about alcohol use is not available in a form that is useful for your clients.

Pregnant Women

15. Would you consider the following to be barriers to women seeking care for alcohol use during pregnancy?

- 15.1 dual diagnoses (e.g., depression, bipolar disorder, panic attacks)
15.2 history of sexual abuse
15.3 history of domestic abuse
15.4 co-dependence (partner/peer/parental substance abuse)
15.5 current violence in the home
15.6 extrinsic barriers (e.g., childcare, housing, transportation, poverty)
15.7 fear of public shame, blame, etc.
15.8 misinformation about the safety of alcohol use during pregnancy
15.9 fear of losing children to partner or child welfare
15.10 systemic racism
15.11 systemic prejudice based on social/economic class
15.12 communication/language barriers
15.13 paucity/absence of addiction treatment services
15.14 paucity/absence of gender-specific addiction treatment services

16. Do you ask all women who are pregnant if they are currently drinking alcohol? Yes No



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17. Please indicate if you are currently using any of the alcohol screening tools or tests listed below in screening prenatal patients for alcohol use. (Please check all that apply.)

T-ACE: Tolerance, Annoy, Cut-down, Eye-opener
 TWEAK: Tolerance, Worry, Eye-opener, Amnesia, (C)Kut down
 CAGE: Cut-down, Annoy, Guilty, Eye-opener
 MAST: Michigan Alcoholism Screening Test
 AUDIT: Alcohol Use Disorders Identification Test

- None
- T-ACE
- TWEAK
- CAGE
- MAST
- AUDIT
- Urine or blood test
- Other (please specify)
- _____
- _____

18. How do you assess the risk of alcohol misuse by patients who report drinking during pregnancy? (Please check all that apply.)

- Standardized screening tool
 (name) _____
- Informal methods
 (describe) _____
- None at all

19. Do you routinely include the following in your interview with patients regarding alcohol use during pregnancy?

	Yes	No
19.1 drinking pattern of partner	<input type="radio"/>	<input type="radio"/>
19.2 family history of alcohol abuse or dependency	<input type="radio"/>	<input type="radio"/>
19.3 personal history of sexual abuse	<input type="radio"/>	<input type="radio"/>
19.4 history of addictions treatment	<input type="radio"/>	<input type="radio"/>
19.5 quantity of intake (alcohol)	<input type="radio"/>	<input type="radio"/>
19.6 frequency of intake (alcohol)	<input type="radio"/>	<input type="radio"/>
19.7 personal history of binge drinking	<input type="radio"/>	<input type="radio"/>
19.8 type of alcohol consumed	<input type="radio"/>	<input type="radio"/>
19.9 history of drinking prior to knowing about pregnancy	<input type="radio"/>	<input type="radio"/>
19.10 evidence of alcohol related birth defects in other children	<input type="radio"/>	<input type="radio"/>

20. Which of the following best describes the advice you currently give pregnant women regarding alcohol use during pregnancy?

- No alcohol is recommended.
- Alcohol is only dangerous during the first trimester.
- A glass of beer or wine in moderation is OK.
- No specific recommendations are given.
- Other (please specify)
- _____
- _____

21. How often do you discuss what the patient thinks "in moderation" means?

- Frequently Sometimes Rarely Never

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22. Please indicate the frequency with which you take each of the following actions when a pregnant woman reports moderate alcohol use (e.g., 3-13 drinks per week):

If this is never reported in your practice, please check box and skip to question 23.

	Always	Usually	Sometimes	Never
22.1 Advise that this level is not harmful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.2 Discuss adverse effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.3 Advise to abstain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.4 Advise to reduce consumption	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.5 Refer for treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.6 Refer to social services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.7 Order a toxicology screen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.8 Take no action	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. Please indicate the frequency with which you take each of the following actions when a pregnant woman reports heavy alcohol use (e.g., 14 or more drinks per week) or binge drinking (5 or more drinks on any one occasion):

If this is never reported in your practice, please check box and skip to the next section.

	Always	Usually	Sometimes	Never
23.1 Advise that this level is not harmful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.2 Discuss adverse effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.3 Advise to abstain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.4 Advise to reduce consumption	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.5 Refer for treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.6 Refer to social services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.7 Order a toxicology screen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.8 Take no action	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Part C
(Mainly related diagnostic issues)

Please consider your own practice over the past 5 years when answering the following questions.

24. In your practice, have you:

- | | Yes | No | If "Yes,"
how many? |
|---|-----------------------|-----------------------|------------------------|
| 24.1 diagnosed any patient as having FAS? | <input type="radio"/> | <input type="radio"/> | <input type="text"/> |
| 24.2 cared for FAS affected patients? | <input type="radio"/> | <input type="radio"/> | <input type="text"/> |
| 24.3 suspected (but did not diagnose) FAS? | <input type="radio"/> | <input type="radio"/> | <input type="text"/> |
| 24.4 referred patients to confirm a diagnosis of FAS? | <input type="radio"/> | <input type="radio"/> | <input type="text"/> |

25. Have you ever reported an FAS diagnosis? Yes No

26. Have you ever reported an FAE diagnosis? Yes No

27. If you answered "Yes" to reporting either FAS or FAE, with whom did you share the information? (Please check all that apply.)

- Education
- Social Services
- Other (please specify)

28. Do you think there should be mandatory reporting of:

- 28.1 FAS? Yes No Don't know
- 28.2 FAE? Yes No Don't know

29. Are these reportable conditions in your province or territory?

- 29.1 FAS Yes No Don't know
- 29.2 FAE Yes No Don't know

30.1 Do you make use of a diagnostic schema in your practice? Yes No

- 30.2 If "Yes," which one of the following do you use?
- Seattle 4 digit diagnostic criteria
- U.S. Birth Defects Surveillance criteria
- American Association of Pediatrics criteria
- Institute of Medicine criteria
- Other (please specify)

31. Do you make use of standardised terminology for diagnosis? Yes No

32. In your opinion, do the following characteristics define FAS?

- | | Yes | No | Don't know |
|--------------------------------------|-----------------------|-----------------------|-----------------------|
| 32.1 prominent forehead | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.2 flat philtrum | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.3 thin upper lip | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.4 thick upper lip | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.5 short palpebral fissures | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.6 upslanting palpebral fissures | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.7 downslanting palpebral fissures | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.8 CNS dysfunction | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.9 prenatal growth deficiency | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32.10 postnatal growth deficiency | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

33. Which of the following items would give you the most accurate information regarding the diagnosis of FAS? (Please select one only.)

- Mother has history of alcohol abuse or dependency
- Small at birth
- Behaviour problems
- Cognitive problems
- Special facial characteristics
- Combination of growth, brain, and facial abnormalities



34. Please indicate whether the following, in your opinion, are associated with or are directly caused by FAS:

	Associated with FAS	Directly caused by FAS	Neither	Don't know
34.1 Long term emotional disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.2 Disrupted school experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.3 Addictions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.4 Legal problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.5 Diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.6 Cleft palate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.7 Hearing problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.8 Alzheimer's	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.9 Attention Deficit Disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.10 Low IQ	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.11 Average IQ	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.12 High IQ	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.13 Albinism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.14 Inappropriate sexual behaviour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

35. Where would you refer suspected patients with FAS?

36. Many doctors do not make the diagnosis of FAS in their practice. Please indicate which of the following factors may contribute to this situation. (Please select all that apply.)

If making the diagnosis would be beyond your scope of practice, please check this box and skip to Question 38.

- Lack of time needed to make diagnosis
- Lack of specific training to make the diagnosis
- Belief that making the diagnosis will not make a difference to the individual
- Other (please specify)

37. Please rate the helpfulness of the following in making an FAS diagnosis, or indicate that they are not available in your community.

	Very helpful	Somewhat helpful	Not very helpful	Not at all helpful	Not available in my community
37.1 Access to a psychologist	<input type="radio"/>				
37.2 Access to educational information	<input type="radio"/>				
37.3 Access to a multidisciplinary team	<input type="radio"/>				
37.4 Outreach clinic with an expert diagnostic team	<input type="radio"/>				
37.5 CME training	<input type="radio"/>				
37.6 Use of Telehealth for diagnosis by an expert diagnostic team	<input type="radio"/>				

38. What do you think are the most commonly held misconceptions about FAS?

39. Where would you seek more information on FAS?





58601



Part D
(Background information)

The following information will be used to help us understand more about health care practitioners, their experience, and their work environment.

40. What is your gender? Male Female

41. What is your age?

42. Marital status: Single
 Married
 Living with a partner
 Divorced
 Separated
 Widowed

43. Number of children:

44. Physicians only: Year of graduation from medical school:

45. Midwives only:

45.1 Are you a graduate of a Canadian Midwifery Education Programme?
 Yes No If "Yes," year of graduation:

45.2 Are you a Michener Pre-Registration graduate?
 Yes No If "Yes," year of graduation:

45.3 Are you a Prior Learning and Assessment (PLEA) registrant?
 Yes No If "Yes," year of graduation:

45.4 Do you have a degree or diploma in Midwifery from another jurisdiction?
 Yes No If "Yes," name of jurisdiction: _____
Year of graduation:

46. What is your primary mode of practice: (Please select only one.)

Solo practice
 Group practice
 Other (please specify) _____

47. Do you have a university appointment of any type? Yes No

48. Do you consider your practice to be:
 Urban Rural

49. What proportion of your practice is: (Note: categories are not mutually exclusive.)

49.1 Aboriginal _____
49.2 Women (aged 16 years or older) _____
49.3 Children (birth to 16 years of age) _____

THANK YOU FOR YOUR ASSISTANCE



58601



Appendix IX: Cover Letter



March 5th, 2002

Dear Physician,

Please find, enclosed, a brief questionnaire about Fetal Alcohol Syndrome (FAS). The purpose of this study is to obtain information from Family Physicians in Saskatchewan regarding knowledge and attitudes towards FAS. The objectives of the study are to determine knowledge level of physicians and to determine if there is a need for further education/information with respect to FAS. The information will be used to reinforce the need for standardized education, training, and diagnostic criteria for FAS with the ultimate goal to improve outcomes of affected children and communities. Although the benefits from this are numerous, none are guaranteed.

Surveys are risk-free, anonymous, and confidential and the return of your completed survey conveys your willingness to consent to the study. These data will be used as part of a research project pioneered by Jocelynn L. Cook, Ph.D. at the University of Saskatchewan and data will be published as part of a Master's of Business Administration thesis project.

Please return the completed questionnaire by March 19th using the stamped pre-addressed envelope provided.

This proposal was reviewed and approved on ethical grounds by the University of Saskatchewan Advisory Committee on Ethics in Behavioral Science Research.

Thank You for your time – I realize the significance of your time limitations and greatly appreciate your participation! If you have any questions, please do not hesitate to contact me.

Best Regards,

Jocelynn L. Cook, Ph.D.

Appendix X: Follow-Up Cover Letter



Jocelynn L. Cook, Ph.D.
Assistant Professor
Departments of Pediatrics and
Obstetrics, Gynecology, and
Reproductive Sciences
University of Saskatchewan
Royal University Hospital
103 Hospital Dr
Saskatoon, SK S7N 0W8
Phone: 306.966.8159
FAX: 306.966.8040
Email: jlc398@mail.usask.ca

April 10th, 2002

Dear Physician,

Please find, enclosed, a brief questionnaire about Fetal Alcohol Syndrome (FAS). The purpose of this study is to obtain information from Family Physicians in Saskatchewan regarding knowledge and attitudes towards FAS. The objectives of the study are to determine knowledge level of physicians and to determine if there is a need for further education/information with respect to FAS. The information will be used to reinforce the need for standardized education, training, and diagnostic criteria for FAS with the ultimate goal to improve outcomes of affected children and communities. Although the benefits from this are numerous, none are guaranteed.

Surveys are risk-free, anonymous, and confidential and the return of your completed survey conveys your willingness to consent to the study. These data will be used as part of a research project pioneered by Jocelynn L. Cook, Ph.D. at the University of Saskatchewan and data will be published as part of a Master's of Business Administration thesis project.

Please return the completed questionnaire by April 24th using the stamped pre-addressed envelope provided. By doing so, your name will be entered into a draw for a \$50.00 gift certificate for Chapters online bookstore.

This proposal was reviewed and approved on ethical grounds by the University of Saskatchewan Advisory Committee on Ethics in Behavioral Science Research.

Thank You for your time – I realize the significance of your time limitations and greatly appreciate your participation! If you have any questions, please do not hesitate to contact me.

Best Regards,
Jocelynn L. Cook, Ph.D.

Appendix XI: Nanson Survey

THE DIAGNOSIS OF FETAL ALCOHOL SYNDROME (FAS) AND FETAL ALCOHOL EFFECTS (FAE): A SURVEY OF PHYSICIAN'S KNOWLEDGE AND CLINICAL APPLICATION

1. How many years have you been practicing medicine? _____ years
2. What is your primary area of medical specialization? _____
3. What is your gender? Male Female
4. Do you feel that your own drinking behavior (or lack of influences your ability to diagnose problem drinking?

Yes	No
-----	----
5. Would the following facts, elicited during an alcohol-use history, lead you to be suspicious of problem drinking?

	Yes	Probably Yes	Probably No	No
Drinking means getting drunk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Embarrassed about behavior when drinking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Impaired driving charges	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frequently hung over or late for work/school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting into fights while drinking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having sex with someone they would not have when sober	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drinking 1 glass of wine daily at dinner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drinking 5 glasses of wine at dinner once/week	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Which one (1) of the following methods would you most often use to screen for alcohol use in women?
 - The CAGE standardized screening test
 - The TWEAK standardized screening test
 - Direct questioning related to frequency of intake
 - Direct questioning related to quantity of intake
 - Biochemical markers (i.e., liver enzymes, corpuscular volume, carbohydrate-deficient transferrin)
 - Other (please specify) _____
7. Which of the following describes the advice you would currently give pregnant women regarding alcohol use in pregnancy (you may select more than one (1) option):
 - The amount of alcohol considered safe for the fetus is unknown
 - No alcohol is recommended throughout pregnancy
 - No alcohol is recommended for the first trimester
 - A glass of beer or wine occasionally is likely not a concern
 - Other, please specify _____
8. During or since training have you (please select all that are true):
 - Diagnosed any children with FAS
 - Diagnosed any children with FAE
 - Suspected (but didn't diagnose) some form of alcohol-related birth defects
 - Referred any children to confirm a diagnosis for FAS/FAE If so, where would you refer to? _____

 - Counseled pregnant women on the use of alcohol during pregnancy
 - Obtained a pregnancy history including alcohol use volunteered by the patient
 - Counseled females of child-bearing age on the use of alcohol

9. In your opinion, from the following list of options, what are the three (3) most important features in order to make the diagnosis of FAS?

- Growth retardation
- Behavioral problems
- Cardiac malformation
- Mental retardation
- CNS neurodevelopmental abnormalities
- Facial dysmorphology
- Confirmed maternal alcohol consumption

10. Please indicate your opinion on each of the following statements:

	Strongly Agree	Tend to Agree	Neutral	Tend to Disagree	Disagree	Don't Know
FAS is an identifiable syndrome (specific diagnostic criteria exist)	<input type="radio"/>					
FAS is easiest to diagnose during childhood	<input type="radio"/>					
Making a diagnosis of FAS can improve treatment plans for the affected child	<input type="radio"/>					
Dysmorphology associated with FAS is permanent	<input type="radio"/>					
FAS is overdiagnosed	<input type="radio"/>					
In general, physicians are sufficiently aware of FAS to make the diagnosis	<input type="radio"/>					
The training <u>you</u> received on FAS diagnosis was adequate	<input type="radio"/>					

11. How sure are you in accurately making a diagnosis of:

	Very Sure	Somewhat Sure	Somewhat Unsure	Very Unsure	Don't Know
Problem Drinking	<input type="radio"/>				
FAS	<input type="radio"/>				

12. You have diagnosed a child with FAS. From the following list, select and RANK the three (3) most important factors in determining the quality of life for this child (with 1 being the most important).

- _____ Absence of violence involving self or others
- _____ Decreased cognitive abilities
- _____ Low adaptive behavior score
- _____ Living in stable and long-lasting home environments of "good quality"
- _____ FAS diagnosis within the first year of life
- _____ FAS diagnosis before the age of 6 years

THANK YOU AGAIN FOR YOUR PARTICIPATION!

Appendix XII: Statistical Analyses

Table 1: Statistical Analysis of FAS Knowledge versus FAE Knowledge

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Chi-Square	0.7	1	0.4	Not significant
Pearson Correlation	0.173		0.076	Not significant
Kendall's Tau b	0.156		0.111	Not significant
Spearman's rho	0.156		0.111	Not significant

Table 2: Statistical Analysis of the effects of Graduation Year on FAS Knowledge

Test	Statistic Value	Degrees of Freedom	p-value	Significance
ANOVA	3.76	2	0.27	Not Significant
Pearson Chi Square	3.63	2	0.162	Not significant
Likelihood Ration	3.66	2	0.161	Not significant
Goodman and Kruskal tau	0.02		0.127	Not significant
Spearman Correlation	0.006		0.954	Not significant

Table 3: Statistical Analysis of the effects of Graduation Year on FAE Knowledge

Test	Statistic Value	Degrees of Freedom	p-value	Significance
ANOVA	3.049	2	0.052	Not significant
Pearson Chi Square	0.005		0.997	Not significant
Likelihood Ration	0.005		0.997	Not significant
Goodman and Kruskal tau	0.000		0.997	Not significant
Spearman Correlation	0.005		0.964	Not significant

Table 4: Statistical Analysis of the effects of Place of Practice on FAS Knowledge

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi 0.793	1	0.373	Not significant
Likelihood Ration	0.800	1	0.371	Not significant
Goodman and Kruskal tau	0.008		0.375	Not significant
Spearman Correlation	-0.088		0.378	Not significant

Table 5: Statistical Analysis of the effects of Place of Practice on FAE Knowledge

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi 0.102	1	0.75	Not significant
Likelihood Ration	0.102	1	0.749	Not significant
Goodman and Kruskal tau	0.001		0.751	Not significant
Spearman Correlation	0.032		0.752	Not significant

Table 6: Statistical Analysis of the Effects of Place of Practice on FAS Diagnosis

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 0.793	1	0.373	Not significant
Likelihood	0.800	1	0.371	Not significant
Goodman and Kruskal tau	0.008		0.375	Not significant

Table 7: Statistical Analysis of the Effects of Place of Practice on FAS Diagnosis-Related Activities

Caring for an FAS affected individual or their family

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 0.2	1	0.01	Significant

Suspecting, but not diagnosing FAS

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 0.07	1	0.78	Not significant

Referring for an FAS diagnosis

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 1.3	1	0.25	Not significant

Table 8: Effect of University Appointment on Knowledge of FAS

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 0.588	1	0.443	Not significant
Likelihood Ratio	0.563	1	0.453	Not significant
Goodman and Kruskal tau	0.006		0.446	Not significant

Table 9: Effect of University Appointment on Knowledge of FAE

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 0.440	1	0.509	Not significant
Likelihood Ratio	1.426	1	0.232	Not significant

Table 10: Effects of Graduation Year, University Appointment, and Place of Practice on Preparedness for Caring for an FAS-affected Individual or their Family

Effect of Graduation Year

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 1.19	1	0.552	Not significant

Effect of University Appointment

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 0.292	1	0.589	Not significant

Effect of Place of Practice

Test	Statistic Value	Degrees of Freedom	p-value	Significance
Pearson Square	Chi- 1.95	1	0.163	Not significant

Appendix XIII: Newspaper Article from the Ottawa Citizen

A drink or smoke during pregnancy shouldn't get you all puffed up

The Ottawa Citizen

Wednesday, July 24, 2002

Page: A16

Section: News

Byline: Rondi Adamson

Column: Rondi Adamson

Source: Citizen Special

Ken Livingstone, the mayor of London (England), found himself in the headlines recently for a reason unrelated to politics. At a party, he saw his pregnant girlfriend smoking, and intervened. Some sort of fight ensued and gossip columnists gleefully reported. A few months back, a pregnant Kate Moss caught it from the press and general public when she was photographed at a party with a drink in her hand. And unknown women are judged. A six-months pregnant friend of mine, two weeks short of 41, recently found herself harangued by a waitress (who looked about 22) when she ordered a beer with lunch. She said, "Listen honey, I'm probably two decades older than you, I'm easily 10 times smarter than you and I have an ob-gyn. So I don't need advice from a waitress." She got her beer. That we should intervene when we see a pregnant woman sniffing gallons of glue, shooting up heroin, guzzling cases of muscatel, smoking packs of cigarettes or bungee-jumping goes without saying. Yes, a woman's body is her own ... up to a point. But Livingstone's girlfriend was having one cigarette, and by all accounts it was the first one she'd had in weeks. Livingstone's behaviour proved he has some "control issues," not that he is a caring father. Of course, smoking at any time, but especially during pregnancy, is stupid and self-destructive. Smoking is in no way good

for you, is vulgar, costly, makes your teeth and fingers turn yellow, increases your chances of getting several diseases and gives you extra wrinkles.

Regular smoking during pregnancy increases chances of miscarriage and crib death, among other things. But there is no proof that a pregnant woman smoking, say, two cigarettes a month, especially when she is beyond the first eight weeks of her pregnancy, is putting her baby at risk.

Drinking, on the other hand, is not stupid or self-destructive. In moderation it is widely agreed to be beneficial to one's health. And the hysteria around fetal alcohol syndrome is just that. Even the physicians who did the initial research and coined the term have said as much. The initial work, done by Ernest Abel and Robert Sokol in the early 1980s, seemed to suggest that even a drop of liquor during gestation would turn a baby into a slobbering, handicapped basket case. That became the received wisdom. The good doctors themselves, though, in 1991, issued a statement saying that "we now estimate that the incidence of FAS in the western world ... is about six times lower than our previous estimate." No one seems to have read that. In studies since, Abel and Sokol have pointed out that FAS is most likely not related to drinking alone, but to combined factors, such as the mother's level of nutrition before and during her pregnancy, her education level, IQ, social class, previous health history, genetic susceptibility to disease, use of drugs and/or frequent smoking. In other words, if a pregnant woman drinks moderately, but also smokes, has an IQ of 80, eats a steady diet of meat and Cheetos and cohabits with a crack addict in a tenement in an inner-city, she is probably

at a higher risk of giving birth to an FAS baby than is a pregnant woman who drinks a couple of glasses of wine a week, doesn't smoke, eats well, has an IQ of 125 and lives with her husband in an apartment on a nice enough street. Well, duh.

No one knows what a safe amount of alcohol during pregnancy is. And if you want to err on the side of caution and not drink at all, more power to you. But even that is not a guarantee your child will be healthy. Preaching to a woman who has a drink or two during pregnancy is unseemly, especially as -- I would argue -- there are far worse things women do to their children after giving birth to them. Not breast-feeding them and sticking them in daycare are but two.

Anecdotal evidence alone should show us that light to moderate drinking during pregnancy is not a cause for concern. Most of our mothers drank during pregnancy. Mine had the occasional martini or brandy Alexander during all seven of hers. And none of us were born with that dreaded "low-birth weight" FAS fearmongers love to talk about. Or were we? Four of us weighed nine pounds, three (including me) weighed in at 10. As mum likes to say, "I'm so glad I drank when I was carrying you all, because just imagine what you would have weighed otherwise."

Rondi Adamson is a Toronto freelance writer.

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