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Substance Abuse

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ISBN  
0-9731323-8-8

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The Centre of Excellence for Special Needs is one of five Centres of Excellence for Children's Well-Being funded by Health Canada.

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## Contents

List of Tables	ii
Acknowledgments	iii
I. Summary	iv
II. Introduction	1
III. Research Purposes	2
IV. Research Objectives and Summary of the Literature	3
Diagnosis of FAS/FAE	3
Difficulty in Diagnosis of FAS/FAE	4
Disabilities of FAS/FAE	5
V. Methods	10
VI. Findings	16
VII. Discussion	36
VIII. References	44
IX. Appendix A: Variable List	48

## List of Tables

1. Age of Children at Time of Diagnosis of FAS/FAE	17
2. Reason for Referral to Dr. Hay	19
3. Developmental and Speech Delays of Children with FAS/ FAE	20
4. Mental Health Diagnoses of Children with FAS/ FAE	22
5. Cognitive Diagnoses of Children with FAS/ FAE	23
6. Physical Diagnoses of Children with FAS/ FAE	25
7. Behavioral Diagnoses of Children with FAS/ FAE	26
8. Neurological Functioning of Children with FAS/ FAE	27
9. Cognitive Functioning of Children with FAS/ FAE	28
10. Affective Functioning of Children with FAS/ FAE	29
11. Behavioral Functioning of Children with FAS/ FAE	30
12. Custody Arrangement of Children with FAS/ FAE	31
13. Number of MCF Placements for Children with FAS/ FAE	33
14. Purpose of Medication Prescribed for Children with FAS/ FAE	34
15. Resources Recommended for Caregivers of Children with FAS/ FAE	35

## **Acknowledgments**

Financial contribution for this project, and ongoing research, comes from the Centres of Excellence for Children's Well-Being Program, Health Canada. The views expressed herein do not necessarily represent the official policy of Health Canada.

The author wishes to thank Dr. Cindy Hardy for her enthusiasm, guidance and expertise; Professor Glen Schmidt for his insight into FAS/FAE; and to Assistant Professor Shereen Ismael for her interest in this research. The author also wishes to thank Dr. Ternowetsky, Jeanette Turpin, Dr. Hay, Dr. Fish and the Child Welfare Research Centre without whom this endeavor may never have begun.

This research is for the many children and their families who have been impacted by FAS/FAE and who were the impetus for this research. I hope this study benefits you by reinforcing the need for resources in your communities that are dedicated to the needs of children with FAS/FAE.



## Summary

The purpose of this study is to describe and compare the demographic and health characteristics, and living arrangements of 83 children with Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) who reside in Prince George and Fort St. James. This study reviews data collected as part of a larger study of 148 children with FAS/FAE conducted by Turpin, Ollech and Hay (1997). The children in this study range in age from 3 months to 16 years and the majority have Aboriginal heritage. In Prince George 63% of the children are male, and in Fort St. James 50% are male. The primary disabilities of children in this study included attention deficit and hyperactivity, delayed development, speech and language deficits, physical problems, and learning disorders and mental retardation. This study profiles the secondary disabilities of mental health problems and parenting problems of the children.



## Introduction

In 1968, Dr. Paul Lemoine and his colleagues from France identified a definite relationship between alcohol use and developmental birth defects. Lemoine's study of 127 children born to alcoholic mothers described four characteristic abnormalities typical of fetal alcohol syndrome: very peculiar facies, increased frequency of malformation, psychomotor disturbances, and growth and height retardation (Elliot & Johnson, 1983). Unfortunately these findings were largely ignored until 1973 when American researchers, Jones and Smith, identified 11 children with similar patterns of craniofacial anomalies, central nervous system (CNS) dysfunctions and deficiencies in growth (Streissguth, 1997b). Alcohol is now recognized as a major and common teratogen (LaDue, Streissguth, & Randels, 1992). Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE) are terms used to describe conditions that result from prenatal exposure to alcohol (Smitherman, 1994). The full-blown syndrome, FAS, is the major expression of a continuum of effects exerted by alcohol on the developing fetus (Greene & Wilbee, 1992). Children with FAE do not manifest all the physical features of FAS, but have a clear history of prenatal alcohol exposure and CNS dysfunction (Streissguth, Barr, Kogan, & Bookstein, 1996).



## Research Purposes

This study is an extension of a larger FAS/FAE study conducted by Turpin et al. (1997) through the Child Welfare Research Center (CWRC) at the University of Northern British Columbia (UNBC). Turpin et al. summarized medical records of 148 children diagnosed with FAS/FAE by one pediatrician in northern BC. Demographic and health characteristics and living arrangements of the children and their birth parents were described (Turpin et al.). Although the 148 children resided in over ten northern communities, Turpin et al. described these children as a group so it is unknown if there are any differences between children residing in different communities. Turpin et al. found the majority of children in their study resided in Prince George, therefore in statistical summaries, the characteristics of the Prince George children may obscure the characteristics of the children from other communities. This study focuses on 83 children who reside in Prince George and Fort St. James who represent 56% of the sample in study conducted by Turpin et al. (1997). The two communities differ in a variety of ways such as total population, on-reserve population, location, and available resources (Statistics Canada, 2000). Possibly the characteristics and resource needs of the children with FAS/FAE also differ.

The purpose of this study is to describe and compare the demographic and health characteristics and living arrangements of 83 children with FAS/FAE who reside in Prince George and Fort St. James. This information will assist in identifying the health, educational and social resource needs of children with FAS/FAE residing in these two communities. In addition any differences in characteristics and resource needs between children residing in these two communities will be identified.

## **IV** Research Objectives and Summary of Literature

The objectives of this research were two-fold: first to document the health, social and educational resource needs of children with FAS/FAE who reside in Prince George and Fort St. James and secondly to determine whether health, social and educational resource needs of children with FAS/FAE differ in the two communities. To this end, a review of the literature will occur pertaining to the disabilities of FAS/FAE, the difficulty in diagnosing FAS/FAE, and the existing diagnosis of FAS/E.

### *Diagnosing FAS/FAE*

Diagnosis of FAS is based on three primary characteristics of the child: (a) CNS dysfunction, (b) a distinctive pattern of craniofacial malformations, and (c) growth deficiency (Clarren & Astley, 1997; Mattson & Riley, 1997). A diagnosis of FAS is assigned to those who have: (a) a clear history of prenatal alcohol exposure, (b) certain dysmorphic features, (c) growth retardation for height and/or weight below the 10<sup>th</sup> percentile of normal growth; and (d) CNS dysfunction. Although CNS dysfunction is variable, it often presents as microcephaly, structural brain anomalies, hyperactivity, developmental delay, attention and/or memory deficits, learning disabilities and mental retardation, motor problems, neurological signs, and/or seizures. Facial malformations include short palpebral fissures, a long smooth philtrum, a thin upper lip, and flat midface. Growth deficiency can include both height and weight, and can persist into adulthood (Streissguth et al., 1997).

A diagnosis of FAE is used to describe those individuals who do not manifest all the physical features of FAS, but have a clear history of prenatal alcohol exposure and CNS dysfunction (Streissguth et al., 1996). Diagnosis of FAE is particularly difficult because the children may not show many of the overt physical symptoms that characterize children with FAS. Kemp, a clinical nurse specialist with the Alberta Alcohol and Drug Abuse Commission, stated accurate diagnosis of FAE children was necessary in order to give them optimum help (as cited in Greene & Wilbee, 1992). Michael Dorris, a parent of three children with FAS, said "diagnosis doesn't solve

our problems, or our children's, but it is healing, it is affirming, it is a candle in a long dark corridor" (1997, p. xxi).

### *Difficulty in Diagnosis of FAS/FAE*

A profound issue is the difficulty of diagnosing FAS/FAE. The clinical features and the degree of alcohol exposure range along a continuum and clinicians have been unable to agree on a simple diagnostic schema to deal with gradations in exposure and in effects (Clarren & Astley, 1997). FAS can be diagnosed at birth, however it is often overlooked in newborns. In a study of medical records of infants born to mothers with documented alcohol abuse during pregnancy, there was a 100% failure to diagnose FAS/FAE (Little, Snell, Rosenfeld, Gilstrap & Grant, 1990). There is no clear dose-response relationship between maternal intake of alcohol and FAS/FAE, and it is unclear whether there is a safe level of alcohol use during pregnancy. There is no consensus on what level of alcohol use, apart from five or more drinks per day, or what pattern of drinking, such as binge drinking, results in FAS/FAE (CCSA, 1996). A factor that compounds the difficulty in diagnosing FAS/FAE is the underreporting of prenatal alcohol exposure (Streissguth, 1997a). Alcohol consumption is difficult to determine, particularly during pregnancy when concerns about the consequences of drinking may lead to significant under-reporting of alcohol use (CCSA, 1996). Access to prenatal care, the stress level and overall health of the mother, the mother's age and nutrition, the genetic resiliency of the infant and the mother, the mother's income and education, and the timing and amount of alcohol consumption are some of the many factors thought to influence the severity of FAS/FAE (Amos, 2000).

Greene and Wilbee (1992) suggest accurate diagnosis of FAS/FAE would be facilitated through development of a universal assessment tool that health professionals can utilize. Although a universal assessment tool is not available, some assessment tools are being developed and utilized in the diagnosis of FAS/FAE. Dr. Hay, a pediatrician in Prince George, utilizes an assessment tool to assist in diagnosing children with FAS/FAE that was adapted from a tool developed by Sunny Hill Hospital in Vancouver, BC (Turpin et al., 1997). The Alberta Clinical Practice Guidelines Program has developed guidelines and diagnostic criteria that can be used for

the diagnosis of FAS (Alberta Partnership on Fetal Alcohol Syndrome, 1999). While these tools are a beginning, more work needs to be done to improve the accuracy of FAS/FAE diagnosis. Children with FAS/FAE and their caregivers often endure years of enormous stress and confusion about why the children behave the way they do because the children are not correctly diagnosed (Greene & Wilbee, 1992).

### *Disabilities of FAS/FAE*

#### Primary Disabilities of FAS/FAE

Streissguth et al. define primary disabilities as “functional deficits that reflect the CNS dysfunctions inherent in the FAS or FAE diagnosis” (1997, p. 27). Prenatal exposure to alcohol can have devastating consequences for children. Children with FAS/FAE often have difficulties with behavioral, cognitive and physical functioning. Growth deficiencies, delayed development, mental retardation, attention deficit, hyperactivity, learning disorders, social and emotional difficulties, vision and hearing deficits, speech and language deficits, facial and skeletal abnormalities, and cardiac anomalies are common problems among children with FAS/FAE (Turpin et al., 1997). According to Mattson and Riley (1997), children with prenatal exposure to alcohol display deficits in verbal learning, language, perception and intellectual development. In a follow-up of a prospective study of 22 children ranging in age from 11.5 to 14 years, Aronson (1997) reports that “a majority of children exposed to abuse levels of alcohol in utero had attention deficits, motor control problems, or both, in pre-adolescence. Specific learning disorders also were very common.” (p. 23).

#### Secondary Disabilities of FAS/FAE

According to Streissguth et al. “secondary disabilities are those that arise after birth and presumably could be ameliorated through better understanding and appropriate interventions” (1997, p. 27). Common secondary disabilities include mental health problems such as depression, disrupted school experiences, problems with parenting, trouble with the law, inappropriate sexual

behaviors, and alcohol and drug abuse. Streissguth et al. (1997) studied six main secondary disabilities:

1. Mental health problems - being diagnosed with a mental health problem or ever having gone to a psychotherapist or counselor for a mental health problem;
2. Disrupted school experience - having dropped out of school or having been expelled or suspended from school;
3. Trouble with the law - ever having been charged or convicted of a crime or been in trouble with the authorities;
4. Inappropriate sexual behavior - having been sentenced to a sexual offenders' treatment program or having repeated problems with inappropriate sexual behaviors;
5. Confinement - ever having been incarcerated for a crime or inpatient treatment for mental health problems; and
6. Alcohol/Drug problems - having alcohol and/or drug abuse problems or having been in treatment for alcohol or drug problems.

Streissguth et al. (1996) found mental health problems were the most prevalent of the secondary disabilities and experienced by over 90% of the participants in their study. Disrupted school experience and trouble with the law were the second most prevalent secondary disabilities and were experienced by 60% of the participants. Inappropriate sexual behavior and confinement were experienced by 50% of the participants, and alcohol and drug problems were noted for 30% of the participants. Rates of secondary disabilities were nearly equal across the sexes for mental health problems, inappropriate sexual behavior, and alcohol and drug problems. Disrupted school experience, trouble with the law, and confinement were experienced more often by males than females. Secondary disabilities, with the exception of mental health problems, occurred more frequently in participants 12 years of age and older. Participants with FAE had higher rates of secondary disabilities when compared to participants with FAS (Streissguth et al., 1996). Children with FAE are more difficult to diagnose than children with FAS and receive fewer services, which may explain the higher rates of secondary disabilities for children with FAE.

## Legal Issues and FAS/FAE

Trouble with the law is a common secondary disability of children with FAS/FAE (Streissguth et al., 1996). Youth with FAS/FAE are likely to have characteristics that bring them into conflict with other people and the criminal law system, or predispose them to become victims of crime. Judge Barnett (1997) stated he has heard many cases where youth affected by FAS/FAE are either charged with crimes or are victims of crimes. Fast, Conry and Looch (1999) estimated between 30 to 60% of juveniles offenders in one BC institution were affected by prenatal exposure to alcohol. LaDue and Dunne (1997) point out children with FAS/FAE have difficulty with comprehension of social rules, impaired ability to connect cause and effect, and have problems learning from past experiences. Behavioral difficulties also include impulsiveness, poor personal boundaries, and being easily influenced.

Unfortunately, many people affected by FAS/FAE who come into contact with the legal system are not recognized as disabled. According to LaDue and Dunne (1997), little knowledge of the deficits associated with FAS/FAE has made it into the legal system. The behavioral and cognitive deficits of youth with FAS/FAE are often not recognized by the courts, and the ability of these youth to understand the consequences of their actions is frequently overestimated. LaDue and Dunne suggest the juvenile court system be allowed enough flexibility to support and assist the youth with FAS/FAE, rather than simply to punish and warehouse them.

## FAS/FAE and Sexual Deviancy

According to Streissguth et al. (1997), inappropriate sexual behavior is a prevalent secondary disability of children with FAS/FAE. Novick (1997) states professionals involved in the assessment and treatment of those charged with sexual crimes usually do not acknowledge the role of FAS/FAE in criminal behavior. If the roles of FAS/FAE are not considered, assessments are inaccurate, treatment is not appropriate, and incarceration is improper. Novick suggests long term monitoring and a structured supportive living environment are required in order to prevent the child with FAS/FAE from re-offending. However, according to Novick, few resources offering such environments are available. Even more important is prevention of inappropriate sexual behavior.

Often legal problems can be avoided if early diagnosis and intervention minimize the problems that occur as a result of the impairments imposed by FAS/FAE.

#### Protective Factors for Disabilities Secondary to FAS/FAE

Streissguth et al. (1997) also identified eight universal protective factors associated with secondary disabilities in FAS/FAE. According to Streissguth et al., "a protective factor is a characteristic or condition that decreases the odds of a secondary disability occurring" (p. 27).

Universal protective factors are those factors that apply to all six of the secondary disabilities.

These eight universal protective factors in order of their strength are:

1. Living in a stable and nurturing home;
2. Being diagnosed before the age of 6 years;
3. Never having experienced violence against oneself;
4. Not having frequent changes of household;
5. Experiencing a good quality home;
6. Being found eligible for disabilities services;
7. Having a diagnosis of FAS (rather than FAE); and
8. Having basic (food and shelter) needs met.

Of these protective factors, the three most powerful are not being a victim of violence, living in a stable and nurturing home, and not having frequent changes of household. Many alcohol-affected children have come from dysfunctional, transient, and abusive living situations.

The study of secondary disabilities by Streissguth et al. (1996) revealed the following problems:

1. Half of the participants over 12 years of age had *not* lived in a stable and nurturing environment;
2. Half of the participants, 12 years and older, had *not* had their basic (food and shelter) needs met
3. Half of the participants had frequent changes of household; and
4. 72% of the participants had experienced physical or sexual abuse, or domestic violence.

Two characteristics associated with a higher rate of secondary disabilities are having an IQ above 70 and having a diagnosis of FAE as opposed to FAS. Those children who have an IQ of lower than 70 qualify for more services than children with a higher IQ. Children with FAS are identified and diagnosed more readily than children with FAE, and are more likely to have received services. The correlations reported by Streissguth et al. (1996) may or may not be causative, however if there is better understanding of these secondary disabilities and the risk and protective factors that exacerbate or ameliorate these disabilities, the quality of life of children living with FAS/FAE and their caregivers can be improved (Streissguth et al., 1997).

# V

## Methods

The data utilized in this study was collected as part of larger FAS/FAE study conducted by Turpin et al. in 1997, and no new data were collected for the research project. The research design, sample selection, confidentiality of patient information, the method used to collect the data and the instrument used to gather the data in the study by Turpin et al. will be described. Outlined in this study are the selected variables that will be summarized and the methods of analysis. Definitions of FAS/FAE and caregivers are also discussed.

### Definitions

Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE) are terms used to describe conditions that result from prenatal exposure to alcohol (Smitherman, 1994). The full-blown syndrome, FAS, is the major expression of a continuum of effects exerted by alcohol on the developing fetus (Greene & Wilbee, 1992). The term Fetal Alcohol Syndrome is used to describe children who exhibit the following characteristics:

1. Growth retardation in at least one of the following areas: (a) low birth weight for gestational age, (b) decelerating weight over time not due to malnutrition, and (c) disproportional low weight to height.
2. Characteristic pattern of facial abnormalities that include features such as small palpebral fissures, a flattened midface, thin upper lip and a smooth philtrum.
3. At least one of the following CNS abnormalities: (a) decreased cranial size at birth; (b) structural brain abnormalities; (c) neurological hard or soft signs (age appropriate) such as impaired fine or gross motor skills, neurosensory hearing loss; or (d) poor hand-eye coordination.
4. There must be a confirmed history of alcohol exposure during the pregnancy.

Children with FAE do not manifest all the physical features of FAS, but have a clear history of prenatal alcohol exposure and CNS dysfunction (Streissguth et al., 1997).

The nomenclature used to describe children with alcohol exposure who do not meet the four criteria for FAS is varied. Initially, FAE was the term that was commonly used, but many medical practitioners believe this term is not specific enough in identifying the extent of disabilities in affected children. Newer terms being adopted include Alcohol Related Birth Defects (ARBD) which describe children who have congenital anomalies, and Alcohol Related Neurodevelopmental Disorder (ARND) which describes children who have CNS damage. Dr. Hay, the pediatrician involved in the Turpin et al. study (1997), uses the term "FAS/FAE continuum" to describe all children who have experienced prenatal exposure to alcohol. In this study, since FAE is a term commonly recognized by both professional and lay people, FAE is used to describe children who exhibit less than the full characteristics of FAS.

According to Streissguth et al. (1997) children who have the benefit of consistent care from their caregivers are less likely to develop secondary disabilities. In this study, the term 'caregivers' is broadly defined to include both biologically related and unrelated caregivers. Related caregivers include birth parents and family members such as grandparents, aunts and uncles. Unrelated caregivers refer to adoptive and foster parents, friends of the family, and group homes. Teachers and FAS workers were seen as resources rather than caregivers, therefore were not included in this definition of caregivers.

#### Research Design/Overview

A descriptive method was used to address the research questions. The nature and extent of FAS/FAE among children residing in Prince George and Fort St. James were examined through analyzing data previously obtained by Turpin et al. (1997) through chart reviews from one local pediatrician's patient records. The demographic and health characteristics and living arrangements of 83 children with FAS/FAE were summarized. The health, social and educational resources recommended by Turpin et al. (1997) were also summarized. Children from the two communities were compared to identify any differences in demographic and health characteristics, living arrangements and resource recommendations. Demographic and health characteristics, living arrangements and resource recommendations and any identified differences allowed the resource needs of the children residing in Fort St. James and Prince George to be identified.

Dr. Hay has been diagnosing children with FAS/FAE utilizing a standard assessment tool since 1993. This diagnostic aid is derived from a tool established by the FAS/FAE Assessment team at Sunny Hill Hospital in Vancouver BC. This tool helps the physician complete a comprehensive assessment of children in a variety of categories, and provides an accurate assessment of whether a child has FAS/FAE.

Using information contained on the FAS/FAE tool, as well as other related patient record information, data for this study were previously collected by Turpin et al. (1997) in four main categories:

1. The demographic characteristics of children with FAS/FAE;
2. The health profiles and medical treatment of the diagnosed children;
3. The living arrangements of children with FAS/FAE; and
4. The resources recommended by the pediatrician to maximize the functioning of the children with FAS/FAE and their caregivers.

Demographic characteristics profile each child using variables such as place of residence, gender, age at the time of diagnosis, and cultural heritage. These characteristics provide an indication of what social and educational services are needed by the children. For example three-year-old Aboriginal children may benefit from an Aboriginal Head Start Program.

The health profiles describe the physical, cognitive and behavioral problems of the children. This includes reason for referral to Dr. Hay, delayed development and speech, accompanying diagnoses such as congenital heart anomalies and respiratory problems, and functional ratings in the neurological, cognitive, affective and behavioral domains of the children. Physical, cognitive and behavioral problems indicate what health resources are needed by the children. For example a child with a cardiac defect would require the services of a pediatric cardiologist.

Resources recommended by Turpin et al. (1997) are described and include prescribed medications and caregiver supports. In addition information was collected on involvement of the Ministry for Children and Families (MCF), who the child currently resides with, and whether current caregivers were single or two parent families. Recommended resources and information about the

living arrangements of children with FAS/FAE gives direct indication of the health, social, and educational resource needs of the children and their caregivers.

### Research Participants

This study utilizes secondary data previously collected by Turpin et al. (1997) from approximately 4,000 patient records from one pediatrician's practice, that of Dr. M. Hay, located in Prince George, BC. The pertinent data were obtained utilizing a chart review of these records. No new data were collected for this study. The children were selected from a sample of children identified as having FAS/FAE by Dr. Hay. All the children were diagnosed between 1993 and 1997 using a standard FAS/FAE assessment tool. Children who were diagnosed as FAS/FAE without the use of the assessment tool, and those whose assessment tool was incomplete, were excluded from the study. Although 148 children from several communities were included in the original study conducted by Turpin et al. (1997), only 49 children currently residing in Prince George and 34 from Fort St. James, for a total sample size of 83 children, are included in this study.

### Procedures

Each patient record was identified using a case number only. No information identifying individual children was used. The names of the children that correspond to our coded record are stored in a locked filing cabinet in Dr. Hay's secured office which is protected by a security alarm system. The identity of the patient records that were utilized in the research are retained by Dr. Hay. Patient records remain in the same office. Approval for this process was obtained from the College of Physicians and Surgeons by Dr. Hay, and the UNBC Research and Ethics Committee for the CWRC FAS/FAE project conducted by Jeanette Turpin (Research Associate) and Sandra Ollech (Community Health Graduate Student).

### Analysis Methods

Four categories of variables were examined in this study: demographic characteristics, health profiles, living arrangements of the children, and recommended resources. These data were coded and entered into the SPSS program by Turpin et al. (1997). See Appendix A for a list

of the study variables. Frequency distribution and measures of central tendency were used to interpret the data.

This study examined four variables regarding demographic characteristics of the children with FAS/FAE:

1. Child's current place of residence (Prince George or Fort St. James);
2. Gender of the child;
3. Age of the child at the time of diagnosis; and
4. Cultural heritage of the child.

Children in the Turpin et al. study (1997) resided in over ten different communities. Information on current place of residence allows this study to focus on the needs of children with FAS/FAE who reside in Prince George and Fort St. James. Since diagnosis of FAS/FAE is difficult and often delayed, information on the reason for the child's referral to Dr. Hay provides important data on resources children may require prior to a diagnosis of FAS/FAE. Gender and age provide information regarding the type of resources that may be required by the children. For example, infants may require developmental services, while eight-year-olds may require educational resources. The cultural heritage of the child gives direction to the need for culturally specific services.

Variables focusing on the health profiles of the children provide data regarding the need for specific health resources. This study examined five health variables:

1. Reason for referral to Dr. Hay;
2. Developmental delays;
3. Speech delays;
4. Accompanying diagnoses - mental health, physical, cognitive, behavioral; and
5. Functional ratings - neurological, cognitive, affective, behavioral.

If children have primary disabilities such as developmental and speech delays, they require early intervention resources from speech and physiotherapists. The accompanying diagnoses of the children also indicate the type of specific health resources they require. For example if some children have cardiac problems, they require the services of a cardiologist. Functional ratings of the children indicate whether the children have no problems with functioning,

or mild, moderate or severe problems. Children who have problems with functioning require resources to assist them in improving their ability to function, and prevent or decrease the development of secondary disabilities.

The third category of variables examined included the living arrangements for children with FAS/FAE. This study examined three variables:

1. Involvement of the Ministry for Children and Families (MCF);
2. Custody arrangements; and
3. Whether child resides in a lone or two parent family.

Information about current custody arrangements such as whether MCF has been involved provides direction regarding the social resources the child and caregivers may require.

The fourth category of variables examined included the resources recommended for children with FAS/FAE and their caregivers by Turpin et al. (1997). This study examined two variables:

1. Resources recommended for the child (prescribed medications); and
2. Recommended caregiver resources.

Children who are prescribed medications, particularly for behavioral purposes, often require additional assessment and intervention from a variety of health, social and educational professionals in addition to follow-up by their physicians. Children with the benefit of consistent care from their caregivers are less likely to develop secondary disabilities. Recommendations that indicate what resources may be required by the caregivers of children with FAS/FAE to enhance the ability of caregivers to provide consistent care are examined.

# VI

## Findings

### Demographic Characteristics of Children with FAS/FAE

This study profiled the demographic and health characteristics, and living arrangements of 83 children with FAS/FAE who resided in Prince George or Fort St. James at the time of their diagnosis of FAS/FAE. Information was collected by Dr. Hay as part of the process of diagnosing the children with FAS/FAE. Demographic characteristics regarding the children included place of residence, age at the time of diagnosis, gender and cultural background. Health characteristics included reason for referral to Dr. Hay, developmental and speech delays, accompanying diagnoses, and problems with functioning. Living arrangements included involvement of the child with the Ministry of Families and Children (MCF), custody arrangements, the status of the caregivers and the number of placements experienced by the children. Resources recommended for children and caregivers by Dr. Hay were also examined.

Information was not collected by Dr. Hay regarding caregivers other than birth parents, consequently information was not available for all caregivers. Much of the demographic information related to birth parents, particularly fathers, was also unknown. This information was unavailable because birth parents had not maintained contact with their children or because birth parents were not present when demographic information was obtained.

### Residence

Of the 83 children in this study, 24 (29%) were born in Prince George and 42 (50%) were born in Fort St. James. Of the 83 children, 17 (21%) additional children were born in other communities and moved to Prince George prior to the diagnosis of FAS/FAE (Turpin et al., 1997). Of the 42 children born in Fort St. James, 8 (19%) moved to Prince George prior to being diagnosed with FAS/FAE. At the time of diagnosis of FAS/FAE, 49 children resided in Prince George and 34 resided in Fort St. James. Of the 49 children who resided in Prince George at the time of diagnosis, 25 (51%) were born in Fort St. James or other communities. Turpin et al. did not examine the reasons for this relocation, but suggested one reason may relate to availability of

resources. Many of the children who are more severely affected with FAS/FAE require a myriad of services that may only be available in a more urban community.

#### Age of the Children at Diagnosis

The data in Table 1 profiled the age of children at the time of diagnosis. The children in this study ranged in age from 3 months to 16 years. This was similar to the age range of birth to 17 years of age found by Turpin et al. (1997). Turpin et al. found 55% of children were diagnosed with FAS/FAE before the age of 8 years. This percentage was even higher for children who resided in Prince George where 70% were diagnosed before age 8 years. In Fort St. James, early diagnosis before age 8 years also occurred for the majority of children where 59% were diagnosed before age 8 years. The literature suggests that early intervention decreases the risk these children will develop secondary disabilities such as mental health problems and criminal justice involvement. Unfortunately, 30% of children residing in Prince George and 41% of children in Fort St. James were not diagnosed until the age of 8 years or older. This indicated a large percentage of children with FAS/FAE in this study did not have the benefit of early diagnosis.

Table 1

#### Age of Children at Time of Diagnosis of FAS/FAE

Years of age	Prince George		Fort St. James	
	Number	Percent	Number	Percent
3 months-3 yrs	18	37	9	27
4-7	16	33	11	32
8-11	11	22	9	26
12-16	4	8	5	15
Total	49	100	34	100

### Gender of the Children

In this study, 63% of the children who resided in Prince George were male and 37 % were female, which mirrored the pattern of 60% males and 40% females found by Turpin et al. (1997). This pattern was not reflected among the children in Fort St. James where equal numbers of children were male and female.

### Cultural Heritage of the Children

Turpin et al. (1997) found that nearly 80% of the 148 children in their study were of Aboriginal heritage. The majority of the children in this study were also of Aboriginal heritage. Of the children who resided in Prince George, 59% were Aboriginal and 39% were Caucasian. In Fort St. James all 34 (100%) of the children were Aboriginal. These data were consistent with the literature which suggests that many northern and remote Aboriginal communities in British Columbia have substantially higher rates of FAS/FAE. However, although no Caucasian children with FAS/FAE were identified in Fort St. James, it is important to recognize FAS/FAE are not exclusively problems among Aboriginal people. Possibly Caucasian children who resided in Fort St. James were not being identified, or were diagnosed by a different pediatrician.

### Health Characteristics of Children with FAS/FAE

Children affected by prenatal exposure to alcohol can present with a variety of health problems. No one is able to predict accurately how much damage will occur as a number of factors such as nutritional status, age of the mother, time and duration of alcohol exposure on the fetus, and metabolism of the mother come into play. Developmental and speech delays were examined, as well as mental, physical, cognitive and behavioral diagnoses and functional ratings of the children with FAS/FAE who resided in both Prince George and Fort St. James.

### Reason for Referral to Dr. Hay

Areas of difficulty among children affected by prenatal exposure to alcohol, which led caregivers to seek out a diagnosis were most often inappropriate or unmanageable behaviors, or delayed development or cognitive problems. The data in Table 2 showed 61% and 56% of the

children who resided in Prince George and Fort St. James respectively were referred to Dr. Hay for behavioral reasons. Twenty percent and 23% of the children from Prince George and Fort St. James respectively were referred for developmental or cognitive problems. Only 12% and 15% of the children from Prince George and Fort St. James respectively were referred for physical problems. The least common reason for referral was due to placement issues which often referred to whether a child should reside with their family of origin or in an alternate care arrangement through MCF. These findings are consistent with those of Turpin et al. (1997).

Table 2  
Reason for Referral to Dr. Hay

Reason for referral	Prince George		Fort St. James	
	Number	Percent	Number	Percent
Behavioral	30	61	19	56
Developmental / cognitive	10	21	8	23
Physical	6	12	5	15
Placement	3	6	1	3
Other	0	0	1	3
Total	49	100	34	100

#### Developmental and Speech Delays

CNS damage from prenatal exposure to alcohol can cause delays and deficits in speech and language, and achievement of developmental milestones. For 15 of the 83 children in this study, it was unknown if they had a developmental or speech delay. Often for children who were diagnosed at a later age, developmental information was not available. Of the 43 children who resided in Prince George for whom information was known, 18 (42%) had a developmental delay (see Table 3). Of the 25 children who resided in Fort St. James for whom information was known, 11 (44%) had a developmental delay. Twenty-three (54%) of the 43 Prince George children, and

11 (44%) of the 25 Fort St. James children had a speech delay (see Table 3). When compared to the findings of Turpin et al. (1997), where 53% of the children had a developmental delay and 51% had a speech delay, children who resided in Prince George and Fort St. James had a slightly lower percentage of delays. Clearly there is a need for developmental and speech resources for many of the children with FAS/FAE since over 40% of the children in this study had developmental and speech delays.

Table 3  
Developmental and Speech Delays of Children with FAS/FAE

Type of delay	Prince George		Fort St. James	
	Number	Percent	Number	Percent
Developmental				
Yes	18	42	11	44
No	25	58	14	56
Total	43	100	25	100
Speech				
Yes	23	54	11	44
No	20	48	14	56
Total	43	100	25	100

*Note.* It is unknown if 6 of the 49 children from Prince George and 9 of the 34 children from Fort St. James (15 children) have a developmental or speech delay.

#### Accompanying Diagnoses

Many children in this study had diagnoses in addition to FAS/FAE that reflected problems that were specific to each child. For example, a child might have received an accompanying diagnosis of post traumatic stress disorder (PTSD), attention deficit with hyperactivity disorder (ADHD), or a heart defect. Dr. Hay used both ADHD and attention deficit disorder (ADD) as diagnoses. These diagnoses would highlight problems that may or may not have been related to the prenatal exposure to alcohol, but were comorbid with the diagnosis of FAS/FAE. The

accompanying diagnoses were categorized into four areas: (a) the data in Table 4 referred to mental health concerns, which involved such concerns as family dysfunction, abuse, and neglect; and such diagnoses such as mood disorder (depression), and PTSD; (b) as shown in Table 5 the cognitive domain included learning disorders, ADD, and deficits in intelligence; (c) the data presented in Table 6 referred to physical problems such as respiratory infections and heart defects; and (d) As shown in Table 7 behavioral difficulties such as ADHD, conduct disorder (CD), oppositional defiance disorder (ODD), and sleep disorder were examined.

#### Mental health diagnoses.

The data in Table 4 indicated 55% of children in Prince George and nearly 70% of children in Fort St. James had a mental health diagnosis, and several children had more than one diagnosis. Family dysfunction, abuse or neglect were by far the most common mental health concerns of the children who resided in Prince George and Fort St. James. Family dysfunction, abuse or neglect were concerns for 17 (35%) of the children in Prince George and 16 (47%) of the children in Fort St. James. Only 19 (39%) and 10 (29%) children had no mental health diagnoses in Prince George and Fort St. James respectively. Children who resided in Prince George had a similar percentage of mental health diagnoses when compared to the children in the study by Turpin et al. (1997). However, children who resided in Fort St. James appeared to have slightly more mental health diagnoses (68%) than children in the study by Turpin et al. (53%). Mental health services, particularly those that focus on family functioning, abuse and neglect are critical for the majority of children with FAS/FAE.

Table 4

Mental Health Diagnoses of Children with FAS/FAE

Mental diagnoses	Prince George		Fort St. James	
	Number	Percent	Number	Percent
Family dysfunction/ abuse & neglect	17	35	16	47
Mood disorder	1	2	0	0
PTSD or grief and loss	3	6	1	3
Socially inappropriate	0	0	2	6
2 of above	4	8	2	6
3 or more of above	2	4	2	6
No mental diagnoses	19	39	10	29
Unknown	3	6	1	3
Total	49	100	34	100

Note. PTSD = Post-traumatic stress disorder.

Cognitive diagnoses.

Although one of the major deficits of children with a diagnosis of FAS/FAE is CNS damage, the data in Table 5 indicated the majority of children who resided in Prince George and Fort St. James did not have a cognitive diagnosis. According to Dr. Hay, many of the children who had difficulty with cognitive functioning had an undiagnosed cognitive disorder (personal communication, December 13, 2000). Cognitive diagnoses are made by psychologists and possibly many of these children did not have a cognitive diagnosis because they had not been assessed and diagnosed by psychologists. Based on the determination of the child's cognitive functioning, Dr. Hay often made recommendations regarding the need for IQ testing in order to obtain a cognitive diagnosis for the child, however due to the limited availability of psychologists the majority of children did not appear to have access to this diagnostic resource.

Among the children who resided in Prince George and Fort St. James, 72% and 47% respectively either did not have a cognitive disorder or had not been diagnosed. Turpin et al. (1997) found 57% of the children did not have a cognitive diagnosis. The two most common groups of cognitive diagnoses among the children who resided in Prince George and Fort St. James were ADD and learning disorders, and mental retardation. Of the children who resided in Prince George, 16% had a diagnosis of ADD or learning disorders, and 10% had a diagnosis of mental retardation. In Fort St. James the percentages were higher where 35% of the children had a diagnosis of ADD or learning disorders, and 12% had a diagnosis of mental retardation. The relatively small number of children with cognitive diagnoses, particularly mental retardation, may be the result of the difficulty in diagnosing cognitive disorders in young children, and the availability of resources for diagnosis of cognitive disorders in older children. This small number of children with a diagnosis of mental retardation has major implications for availability of resources since children must have an IQ of below 70 to qualify for many resources.

Table 5  
Cognitive Diagnoses of Children with FAS/FAE

Cognitive diagnoses	Prince George		Fort St. James	
	Number	Percentage	Number	Percentage
ADD/LD	8	16	12	35
Mental retardation	5	10	4	12
Two or more of above	1	2	2	6
No cognitive disorder or not diagnosed	35	72	16	47
Total	49	100	34	100

Note. ADD = Attention deficit disorder. LD = Learning disability.

### Physical diagnoses.

The data in Table 6 indicated the majority of children in this Study had more than one accompanying physical diagnoses. For children who resided in Prince George, 45% had two, three or more physical diagnoses compared to 29% of children who resided in Fort St. James. Prince George children had a higher percentage and Fort St. James children had a lower percentage of two or more physical diagnoses when compared to the children in Turpin et al.'s (1997) study. Turpin et al. found 37% of the children had two or more systems affected. The single most common group of diagnoses was respiratory, and ear, nose and throat (ENT) disorders for 12% and 15% of children who resided in Prince George and Fort St. James respectively. Only 25% of Prince George children and 32% of Fort St. James children had no accompanying physical diagnoses. Turpin et al. found only 28% of the children in their study had no physical diagnoses. Possibly the children who resided in Prince George were more severely affected by FAS/FAE and therefore had more physical diagnoses. Another possibility is children who had more physical diagnoses moved to Prince George because of the greater need for medical services. The majority of children with FAS/FAE had a variety of accompanying physical diagnoses and required an array of medical services.

Table 6

Physical Diagnoses of Children with FAS/FAE

Physical diagnoses	Prince George		Fort St. James	
	Number	Percent	Number	Percent
Respiratory/ENT	6	12	5	15
Head/eyes/dental	2	4	1	3
Heart	2	4	2	6
Elimination/GU/GI	3	6	3	9
Neuromuscular/ skeletal	0	0	1	3
2 of above	16	33	7	20
3 or more of above	6	12	3	9
Other	2	4	1	3
No problem	12	25	11	32
Total	49	100	34	100

Note. ENT = Ear, nose and throat. GU = genitourinary. GI = gastrointestinal

Behavioral diagnoses. The data in Table 7 indicated the majority of children who resided in Prince George and Fort St. James had a behavioral diagnosis. In total, 71% of the children who resided in Prince George and 77% of the children who resided in Fort St. James had a behavioral diagnosis. At the time the children in this study were diagnosed by Dr. Hay, the behavioral diagnoses were made using the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (1987) third edition, revised. These findings for the children in Prince George and Fort St. James were slightly higher when compared to Turpin et al. (1997) who found 68% of the children in their study had a behavioral diagnosis. Of the children who resided in Prince George and Fort St. James, 45% and 65% respectively had a diagnosis of ADHD. ADHD, either alone or in combination with other disorders, accounted for 69% and 71% of behavioral diagnoses among children in Prince George and Fort St. James respectively.

Table 7

Behavioral Diagnoses of Children with FAS/FAE

Behavioral diagnoses	Prince George		Fort St. James	
	Number	Percentage	Number	Percentage
ADHD	22	45	22	65
CD &/or ODD	1	2	0	0
ADHD & CD/ODD	9	18	2	6
ADHD & other	1	2	0	0
ADHD & CD/ODD & other	1	2	0	0
Sleep disorder	1	2	1	3
Anger management	0	0	1	3
No behavioral diagnosis	14	29	8	23
Total	49	100	34	100

Note. ADHD = Attention deficit hyperactivity disorder. CD = Conduct disorder. ODD = Oppositional defiance disorder.

Problems with Functioning

Further evidence of the impact of FAS/FAE on the child was found in the functional ratings assigned by the diagnosing physician. When assessing neurological, cognitive, behavioral and affective ability the diagnosing physician rated the child's functioning as 'No Problem', 'Mild', 'Moderate', or 'Severe' problem.

Neurological functioning

The neurological rating examined such abilities as balance, coordination, gait, movement, and reflexes, among others. The data in Table 8 indicated that although prenatal exposure to alcohol results in CNS damage, the majority of children in this study did not have any problems

with neurological functioning. Of the children who resided in Prince George and Fort St. James, 78% and 82%, respectively, did not have any problems with neurological functioning. Of the children in both communities, 12% had mild problems with neurological functioning, and no children had severe problems. For a small percentage of the children it was unknown if the child had a neurological problem, or the child was too young to accurately assess. The findings of this study were similar to the findings of Turpin et al. (1997) who found 79% of the children in their study had no problem with neurological functioning, and 13% had mild problems.

Table 8  
Neurological Functioning of Children with FAS/FAE

Problem	Prince George		Fort St. James	
	Number	Percent	Number	Percent
None	38	78	28	82
Mild	6	12	4	12
Moderate	3	6	1	3
Severe	0	0	0	0
Unknown	2	4	1	3
Total	49	100	34	100

Cognitive functioning.

Another indication of the CNS damage related to prenatal exposure to alcohol is the cognitive functioning of the child. Assessment of cognitive functioning included intelligence and the ability to learn. Information regarding the cognitive functioning of the children came from a variety of sources such as reports regarding infant development for very young children. For school aged children, psychometric testing and school records, and reports from teachers and parents regarding the intellectual and learning performance of the child provided information regarding cognitive functioning. Based on the degree of reported difficulty with intellectual and learning performance and the consistency of problems both at school and home, the child may be identified

as having problems with cognitive functioning. As shown in Table 9, 43% of the children in Prince George and 41% of the children in Fort St. James had problems with cognitive functioning. Fortunately, only 4% of the Prince George children and 9% of the Fort St. James children had severe problems with cognitive functioning. Turpin et al. (1997) found 38% of the children in their study had problems with cognitive functioning, and information was unknown for 47% of the children. For 41% of the children who resided in Prince George, and 50% of the children who resided in Fort St. James, their cognitive functioning was either unknown or the child was too young for an accurate assessment. The high percentage of children who had unknown cognitive functioning may be due to the lack of information available from the variety of sources, particularly psychometric testing.

Table 9  
Cognitive Functioning of Children with FAS/FAE

Problem	Prince George		Fort St. James	
	Number	Percent	Number	Percent
None	8	16	3	9
Mild	10	21	5	14
Moderate	9	18	6	18
Severe	2	4	3	9
Unknown	20	41	17	50
Total	49	100	34	100

Affective functioning.

Assessment of affective functioning focused on the child's age-appropriate emotional responsiveness in day to day situations. Problems in this area usually manifested in depression, oppositional disorders and manic behavior. As shown in Table 10, 50% of the children in both communities had problems with affective functioning. Almost equal percentages of children in Prince George and Fort St. James had mild or moderate problems with affective functioning at 22%

and 25% respectively. Among the Fort St. James children, the largest group of children (29%) had moderate problems with affective functioning. The findings of this study were similar to the findings of Turpin et al. (1997) where 51% of the children had problems with affective functioning.

Table 10

Affective Functioning of Children with FAS/FAE

Problem	Prince George		Fort St. James	
	Number	Percent	Number	Percent
None	19	39	13	38
Mild	11	22	5	15
Moderate	12	25	10	29
Severe	2	4	2	6
Unknown	5	10	4	12
Total	49	100	34	100

Behavioral functioning

This category addressed the child's behavior including hyperactivity, impulsivity, ability to learn from mistakes, and the ability to control anger. As shown in Table 11, 78% and 76% of children who resided in Prince George and Fort St. James respectively had problems with behavioral functioning. These findings were similar to the percentage of 74% found by Turpin et al. (1997). In both communities the largest group of children (35%) had moderate problems with behavioral functioning. For children in Prince George and Fort St. James, 18% and 23% had severe problems with behavioral functioning. Turpin et al. found 25% of children had severe problems with behavioral functioning. Children with behavior problems are at a higher risk for abuse as they severely challenge caregivers' coping abilities. In addition, inability to manage such behaviors as anger, impulsivity and an inability to connect cause and effect result in children with FAS/FAE being in trouble with the law more often than other children.

Table 11

Behavioral Functioning of Children with FAS/FAE

Problem	Prince George		Fort St. James	
	Number	Percent	Number	Percent
None	8	16	5	15
Mild	12	25	6	18
Moderate	17	35	12	35
Severe	9	18	8	23
Unknown	3	6	3	9
Total	49	100	34	100

Living Arrangements for Children with FAS/FAE

A consistent and nurturing living arrangement is the foundation for all children to grow up and lead healthy, productive lives. This is particularly true for children with FAS/FAE. The findings of a study conducted by Streissguth et al. (1996) suggest three universal protective factors that help prevent the development of secondary disabilities are : (a) living in a stable and nurturing home; (b) not having frequent changes of household; and (c) having basic (food and shelter) needs met. These secondary disabilities include mental health problems, disrupted school experiences, and involvement with the criminal justice system.

Involvement with Ministry for Children and Families

Caregivers of children with FAS/FAE often turn to MCF for assistance in managing their children. In this study, no distinction was made as to whether MCF involvement was a child protection concern or a request for voluntary support services. Sixty seven percent (33) of the children who resided in Prince George, and 74% (25) of the children who resided in Fort St. James were currently receiving services from MCF, or had been involved with MCF in the past. Turpin et al. (1997) found 74% of the children in their study had involvement with MCF.

### Custody Arrangements

Children with FAS/FAE lived in a variety of custody arrangements. As shown in Table 12, the majority of children from Prince George (59%) and Fort St. James (68%) did not reside with their family of origin. These other custody arrangements included extended families, adoptive families, and foster families and group homes. One child from Prince George was in the Youth Custody Centre. Forty one percent of Prince George children resided with their family of origin, and an additional 22% resided with extended family or an adoptive family. The pattern of custody arrangements differed somewhat in Fort St. James. Thirty two percent of children in Fort St. James resided with their family of origin and only 9% resided with extended family. No children from Fort St. James resided with an adoptive family. The majority of children from Fort St. James (59%) resided in foster care or a group home, compared to only 35% of children from Prince George. Turpin et al. (1997) found 51% of the children in their study resided with foster families or group homes.

Table 12  
Custody Arrangements of Children with FAS/FAE

Custody arrangements	Prince George		Fort St. James	
	Number	Percent	Number	Percent
Family of origin	20	41	11	32
Extended family	9	18	3	9
Adoptive family	2	4	0	0
Foster family/group home	17	35	20	59
Jail	1	2	0	0
Total	49	100	34	100

### Caregiver Status

Due to the multitude of problematic behaviors exhibited by many FAS/FAE children, they are often difficult to parent. Impulsivity, lack of ability to associate cause and effect, aggression and fearlessness are only a few among many disruptive behaviors that can burn out even the best parents. Parenting is challenging enough for two parents with healthy children. Parenting children with FAS/FAE is an even greater challenge, particularly for lone parents. In lone parent families, the single caregiver often carries this burden alone. Help in parenting children with FAS/FAE is often necessary particularly for children who reside in lone parent families.

When the status of caregivers was explored, only 31 children from Prince George and 14 children from Fort St. James for a total of 45 children were included. These 45 children were being parented by their family of origin, or extended or adoptive families at the time the children were diagnosed with FAS/FAE. The other 38 children were being parented by foster families and no information regarding caregiver status was available. Of the children from Prince George, 20 (65%) resided with a lone caregiver. In Fort St. James the pattern was reversed where only 4 (29%) children resided with a lone caregiver. Children from Prince George lived with a lone caregiver much more often than children from Fort St. James. Turpin et al. (1997) found 45% of the children in their study resided with a lone caregiver. The children from Prince George resided with a lone caregiver more often than the children in Turpin et al.'s study.

### Number of MCF Placements

As shown in Table 13, the majority of children in foster care had been moved more than once. Number of placements were identified at the time the children were initially assessed by Dr. Hay. Thirty eight percent of the 49 children from Prince George and 26% of the 34 children from Fort St. James had two or more placements. The largest number of placements was 10 for a child from Prince George. Of the 49 children from Prince George and the 34 children from Fort St. James, 4% and 21% respectively had an unknown number of placements. Due to the large percentage of children from Fort St. James who had an unknown number of placements, it is possible the percentage of children with two or more placements could be higher. Turpin et al. (1997) found 41% of the children in their study had two or more placements, and 14% had an

unknown number of placements. Thirty five percent of the children from Prince George and 32% of the children from Fort St. James had no placements through MCF. Turpin et al. found 25% of the children in their study had no placements through MCF.

Table 13

Number of MCF Placements for Children with FAS/FAE

Placements	Prince George		Fort St. James	
	Number	Percent	Number	Percent
One	11	23	7	21
Two or three	4	8	1	3
Four to seven	3	6	3	9
Nine or ten	2	4	0	0
Unknown	2	4	7	21
Unknown but several	10	20	5	14
Not applicable	17	35	11	32
Total	49	100	34	100

Resources for Children with FAS/FAE and Their Caregivers and Resources for Children with FAS/FAE

Following assessment and diagnosis of the children with FAS/FAE, Dr. Hay offered recommendations and suggestions to benefit the children. One of Dr. Hay's recommendations was for medications. As shown in Table 14, 65% and 68% of the children in this study resided in Prince George and Fort St. James, respectively, were prescribed medication. For 41% of Prince George children and 32% of Fort St. James children the purpose for prescribed medications was behavioral. Turpin et al. (1997) found 30% of the children in their study were prescribed medication for behavioral purposes. For 18% of Prince George children and 27% of Fort St. James children the purpose for prescribed medication was physical. Turpin et al. found 18% of the

children in their study were prescribed medication for physical purposes. Only one child in Prince George and none in Fort St. James were prescribed medication for the purposes of mental health. Turpin et al. found only 3 of the children in their study were prescribed medication for mental health purposes. Four percent of Prince George children and 9% of Fort St. James children were prescribed medication for more than one purpose. The findings of this study were similar to Turpin et al. who found 10% of the children in their study were prescribed medication for more than one purpose.

Table 14

Purpose of Medications Prescribed for Children with FAS/FAE

Purpose of medications	Prince George		Fort St. James	
	Number	Percent	Number	Percent
Physical	9	18	9	27
Behavioral	20	41	11	32
Mental health	1	2	0	0
Two or more purposes	2	4	3	9
No prescribed medications	17	35	11	32
Total	49	100	34	100

Resources for Caregivers

The manifestations of FAS/FAE are difficult to cope with on a daily basis, therefore often the most immediate resource requirement for caregivers is for respite care. If adequate respite care resources are not available, there is a possibility the living arrangements for the child may break down. Dr. Hay recommended a variety of resources to assist these caregivers, and as a preventative measure in averting break down of the living arrangements of the children with FAS/FAE. As shown in Table 15 resources were recommended by Dr. Hay for caregivers who resided in Prince George and Fort St. James. Examples of recommended caregiver resources included respite, home support, parenting classes, counseling, support groups, and literature.

Turpin et al. (1997) had similar findings in terms of recommended resources for caregivers. Often more than one of these resources were recommended. It is unknown however, whether the caregiver(s) followed up on these recommendations or whether the resources were available in the child's home community. The data in Table 15 indicated 39% of caregivers from Prince George and 61% of caregivers from Fort St. James were not recommended any resources. Dr. Hay indicated recommended resources may have been discussed with caregivers and not necessarily noted in the child's chart.

Table 15

Resources Recommended for Caregivers of Children with FAS/FAE

Resources	Prince George		Fort St. James	
	Number	Percent	Number	Percent
Counseling/support	2	4	1	3
Education/literature	14	29	5	15
Respite/home care/ parenting classes	3	6	2	6
Two or more	11	22	5	15
No noted resources	19	39	21	61
Total	49	100	34	100

# VII

## Discussion

### Primary Disabilities of Children with FAS/FAE

Streissguth et al. define primary disabilities as “functional deficits that reflect the CNS dysfunctions inherent in the FAS or FAE diagnosis” (1997, p.27). As seen among the children examined in this study, primary disabilities included attention deficit and hyperactivity, delayed development, speech and language deficits, physical problems, and learning disorders and mental retardation.

### Attention Deficit and Hyperactivity

This study shows that ADHD, either alone or in combination with other disorders such as CD and ODD, is by far the most common behavioral diagnosis of the children from both communities. Approximately three-quarters of the children in this study have behavioral diagnoses and have problems with behavioral functioning. In addition, the majority of children from both communities were referred to Dr. Hay for behavioral concerns. The percentages of children with problems with behavioral functioning and behavioral diagnoses are consistent among the children from both Fort St. James and Prince George. Clearly there is a need for resources in Prince George and Fort St. James that address the behavioral issues of children with FAS/FAE.

### Developmental and Speech Delays

This study indicates that a sizable portion of children diagnosed with FAS/FAE have developmental and speech delays among children from both Prince George and Fort St. James. Developmental delays was the second most common reason for referral to Dr. Hay. This number of children with delays points to the need for developmental and speech resources in both communities.

### Physical Problems

This study profiles the physical health problems of the children with FAS/FAE. The children have physical health problems that may be related to their prenatal exposure to alcohol,

and comorbid diseases as well. Examples of illnesses include respiratory and ear, nose and throat; head or eyes, heart, elimination and neuromuscular diseases. The majority of children from both communities had one, two or more physical diagnoses, particularly the children from Prince George. Only a small number of the 83 children in this study were referred to Dr. Hay for a physical problem, however nearly three quarters of the children had one or more physical diagnoses. It is unclear if these physical problems were not being diagnosed by the referring family physicians, or the children were being referred for a concern that was viewed as more of a priority than the physical illnesses of the children. Children with FAS/FAE require services that can assess, diagnose and treat health problems in addition to FAS/FAE.

#### Learning Disorders and Mental Retardation

This study indicates some children have cognitive diagnoses such as learning disorders or mental retardation. Twice as many children who reside in Fort St. James have learning disorders or ADD when compared to the children who reside in Prince George. The percentage of children with a diagnosis of mental retardation is small and nearly the same when children from both communities are compared. Considering the impact of prenatal exposure to alcohol on the CNS, it appears the percentage of children with a diagnosis of mental retardation should be higher. Children with cognitive dysfunctions may go undiagnosed because of difficulties in obtaining psychological assessments.

This study also indicates the children with FAS/FAE have problems with cognitive functioning, although for nearly half of the children their cognitive functioning is unknown. Children with cognitive diagnoses and problems with cognitive functioning require resources such as individualized plans for education, and learning assistance teachers, and teachers' aides to provide one-on-one direction and supervision. Due to the large number of children who appear to have difficulty with cognitive functioning, but have not been diagnosed with a cognitive disorder, the major resource need appears to be access to a psychologist who is able to provide assessment and diagnosis of cognitive disorders such as mental retardation. This is particularly critical since access to some resources is dependent upon the child's level of IQ.

## Secondary Disabilities of Children with FAS/FAE

According to Streissguth et al. "secondary disabilities are those that arise after birth and presumably could be ameliorated through better understanding and appropriate interventions" (1997, p.27). Common secondary disabilities include mental health problems, problems with parenting, trouble with the law, disrupted school experiences, inappropriate sexual behaviors, and alcohol and drug misuse. This study profiled mental health problems of the children, parenting problems and identified one child who had trouble with the law. This study had limited information regarding the experiences the children had with school disruptions, inappropriate sexual behaviors, and drug and alcohol misuse.

Three secondary disabilities that are identified among the children in this study are mental health problems, problems with parenting and trouble with the law. Many of the children have mental health diagnoses, family dysfunction and abuse and neglect concerns, and one child was in jail. Data regarding disrupted school experience is not available for the children in this study, however children who have problems with behavioral and cognitive functioning likely have disrupted school experiences. Children with FAS/FAE require services that address secondary disabilities related to the diagnosis of FAS/FAE.

## Mental Health Problems

This study identifies the majority of children with FAS/FAE in both Prince George and Fort St. James have mental health diagnoses. The percentages of children with mental health diagnoses and problems with affective functioning is similar among the children who reside in Prince George and Fort St. James. Family dysfunction, and abuse and neglect are by far the most prevalent mental health concerns among the children from both communities. This study points to the need for mental health services not only for the children who are experiencing social and emotional difficulties, but for the caregivers of the children as well.

## Protective Factors for Disabilities Secondary to FAS/FAE

Streissguth et al. (1997) identified eight universal protective factors associated with secondary disabilities in FAS/FAE. According to Streissguth et al., "a protective factor is a

characteristic or condition that decreases the odds of a secondary disability occurring” (p. 27). Universal protective factors are those that apply to all six of the secondary disabilities. The three most powerful protective factors that are addressed are living in a stable and nurturing home, not having frequent changes of household, and not being a victim of violence. In addition to the three most powerful protective factors, the protective factor of early diagnosis will be addressed.

#### Frequent Changes of Household

While this study did not examine the length of time children resided in each of their living situations, this study indicates many children have the experience of having frequent placements through MCF. The majority of the children from Prince George and Fort St. James do not live with their family of origin. Many of the children live with foster parents or in a group home, particularly those children who reside in Fort St. James where over half of the children reside with a foster family. Many of the children in this study from Prince George and Fort St. James have had two or more placements. In addition, some of the children have experienced an unknown number of placements, particularly among children residing in Fort St. James. It appears that a large percentage of the children in this study do not experience the benefit of the protective factor of not having frequent changes of household.

The findings of this study show many children experience PTSD, affective disorders, grief and loss issues, and mood disorders which can be related to the frequent changes of placements many of the children experience. This study shows one third of the children residing in Prince George and nearly half of the children residing in Fort St. James have been diagnosed with the mental health concern of family dysfunction, abuse or neglect. Other mental health disorders include mood disorder, post-traumatic stress disorder, and grief and loss. Some children from Prince George and Fort St. James have two or more mental health diagnoses. Less than a third of the children from Prince George and from Fort St. James did not have a mental health diagnosis. This study also indicates that half of the children from Prince George and Fort St. James have mild, moderate or severe problems with affective functioning.

### Living in a Stable and Nurturing Home

Many children in this study do not have the benefit of living in a stable and nurturing home. For the 45 children in this study who are parented by their family of origin, or extended or adoptive families, 65% of the children from Prince George are parented by a lone caregiver. In Fort St. James 29% of children reside with a lone caregiver. Many children experience instability of the home environment related to an absent parent. The majority of children in this study currently receive services from MCF or had been involved with MCF in the past. Involvement with MCF may indicate the majority of children experience an unstable and non-nurturing home environment at least some of the time. This study indicates many children suffer negative consequences such as PTSD, affective disturbance, grief and loss, and mood disorders related to living in an unstable and non-nurturing home. From the findings of this study, it appears the majority of the children from both communities do not have the benefit of nurturing and stable homes.

### Victims of Violence

The findings from this study indicate many of the children from both communities experience family dysfunction, abuse or neglect. Children who reside with dysfunctional families are often victims of family violence. Witnessing or being a victim of violence can lead to PTSD, affective disturbance, grief and loss and mood disorders. This study provides clear evidence children with FAS/FAE who reside in Prince George and Fort St. James suffer a multitude of negative consequences related to abusive, unstable, non-nurturing homes.

Children with FAS/FAE who reside in Prince George and Fort St. James do not have the benefit of the three most powerful protective factors: living in a stable and nurturing home, not having frequent changes of household, and not being a victim of violence. This study clearly indicates the majority of children experience the secondary disability of mental health diagnoses. Resources that assist caregivers in maintaining stable and nurturing homes are critical for supporting the well being of children with FAS/FAE and their caregivers.

### Early Diagnosis of FAS/FAE

Early intervention requires recognition of children with FAS/FAE, and early diagnosis. Findings from this study indicate that while many children from Prince George and Fort St. James are identified early and have the opportunity to participate in early intervention programs, a large number of children are not diagnosed until they are 8 years of age and older. If developmental and speech interventions are to be effective, intervention needs to begin early when the child is as young as possible. Diagnosis after the age of 8 years does not allow this group of children to gain the benefits of early developmental and speech intervention. This study indicates that while a large percentage of children are diagnosed with FAS/FAE before the age of 8 years, one third of the children residing in Prince George and nearly half of the children residing in Fort St. James are not diagnosed until age 8 or older. It has been recognized that optimal outcomes for children with FAS/FAE are predicted for those who are assessed early and have the benefit of appropriate intervention. In order for this to occur, diagnostic resources need to be available to children residing in Prince George and Fort St. James.

### Aboriginal Heritage and Culturally Appropriate Resources

The demographic profile of the children in this study indicates the majority of children diagnosed with FAS/FAE who reside in Prince George and particularly Fort St. James are of Aboriginal heritage. This points to the need for resources that provide culturally appropriate services.

### Differences between Children Residing in Prince George and Fort St. James

This study shows children with FAS/FAE have a variety of disabilities that require a broad range of resources. While the children who reside in Prince George and Fort St. James are similar in many aspects, they do differ. For example, nearly one quarter of the children who were born in Fort St. James relocated to Prince George prior to diagnosis of FAS/FAE. None of the children born in Prince George relocated to Fort St. James. The children in Fort St. James are all Aboriginal, whereas just over half of the children who reside in Prince George are Aboriginal. The gender split among the children from Prince George is approximately 60% male, however there are

an equal number of males and females in Fort St. James. More of the children from Prince George reside with either their family of origin or extended family, and more children in Fort St. James reside with foster families. More children in Fort St. James have an unknown number of placements through MCF. More children in Prince George reside with a lone caregiver, and children in Fort St. James are more likely to live with two caregivers. More children in Prince George have physical diagnoses, and more children in Fort St. James have cognitive diagnoses. More children are diagnosed with FAS/FAE before the age of 8 in Prince George than in Fort St. James.

The children from Prince George and Fort St. James are also similar in many aspects. The age range, the reasons for referral and the percentage of developmental and speech delays are similar. Most of the children in both communities do not reside with their family of origin, the most common mental health diagnosis is family dysfunction, and a similar percentage of children from both communities have been involved with MCF. Children from both communities were similar in terms of cognitive, neurological, behavioral and affective functioning. In both communities, the majority of children have no problems with neurological functioning. The children from both communities had the same behavioral diagnoses and medications were prescribed for the same purposes, typically behavioral or physical purposes.

Children with FAS/FAE from Prince George and Fort St. James need a broad range of health, social and educational resources that will address primary and secondary disabilities related to FAS/FAE. These children also require services that will address the protective factors that may help prevent or diminish the impact of secondary disabilities. The need for resources that ameliorate the impact of FAS/FAE and improve the lives of children and their caregivers is fundamental.

### Study Limitations

The Turpin et al. (1997) study described children with FAS/FAE in one pediatrician's practice. Turpin et al. were not able to determine the prevalence of FAS/FAE in Prince George and Fort St. James. The health, social, and educational resource needs of the caregivers can not be derived from the characteristics of the caregivers since this information is unknown for the majority

of caregivers. No data regarding the characteristics of caregivers is available for other than birth parents, and the majority of the children did not reside with their birth parent(s) at the time of diagnosis, therefore information regarding the characteristics of the majority of caregivers is unknown. No direct information regarding some of the common secondary disabilities related to FAS/FAE was collected. For example there was no information regarding criminal offenses committed by the children, how many school suspensions the children had experienced, or how many children had demonstrated inappropriate sexual behavior.

In this study no distinction was made as to whether MCF involvement was a child protection issue or a request for voluntary support services. This study was not able to determine how many children were in the care of MCF in order to access services.

## Conclusion

Although the incidence and prevalence of FAS/FAE is difficult to establish, estimates indicate FAS/FAE are significant problems among northern communities. Children with FAS/FAE have varying degrees of difficulty with primary and secondary disabilities as a result of prenatal exposure to alcohol. Streissguth et al. (1997) identified eight protective factors that can decrease the odds of a secondary disability occurring. Health, social and educational resources may ameliorate the effects of primary disabilities, and may prevent the development of secondary disabilities. The availability of resources for children with FAS/FAE is an issue, particularly for children who reside in northern and rural communities. There is a need for a broad-based assessment of the status of current health, social and educational services for children in Prince George and Fort St. James.

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Appendix A  
Variable List

## Variable List

Current place of residence of the children

Prince George

Fort St. James

Gender of the children

Female

Male

Children's age at time of diagnosis - ages range from 3 months to sixteen years

Cultural heritage of the children

Aboriginal

Caucasian

Reason for referral to Dr. Hay

Behavioral

Developmental

Physical problem

Placement issue

Other

Developmental delay

Yes

No

Speech delay

Yes

No

Accompanying diagnoses:

Mental health

Family dysfunction

Mood disorder

Post-traumatic stress disorder/grief/loss

Socially inappropriate

Combination of 2, 3 or more

None

Unknown

Physical

Respiratory/Ear/nose/throat

Head/eyes

Heart

Elimination problems

Neuromuscular

Combination of 2, 3 or more

Other

None

Cognitive

Attention Deficit Disorder (ADD)/ learning disability

Mental retardation

Combination of 2, 3 or more

No cognitive disorder or not diagnosed

Behavioral

ADHD

Conduct disorder (CD) &/or oppositional defiance disorder (ODD)

Sleep disorder

Anger management

Combinations of above

None

Functional rating - Neurological, Cognitive, Affective, Behavioral

No problem

Mild problem

Moderate problem

Severe problem

Unknown

Ministry of Children and Families involvement

Yes

No

Has been involved in the past

Current custody arrangements

Family of origin - Birth parent(s)

Extended family - e.g. grandparent(s), aunt, uncle

Adopted

Foster care/group home

Other - e.g. jail

Caregiver status

One parent

Two parents

N/A in non-related foster care

Number of MCF placements

- One
- Two or three
- Four to seven
- Nine or ten
- Unknown
- Unknown but several
- Not applicable

Purpose of medications prescribed for the children

- None
- Physical
- Behavioral
- Mental health
- Two or more purposes

Caregiver resources

- Counseling/support group
- Education/literature
- Respite/home care services/parenting course
- Two or more
- No noted resources