Decoding the FASD Enigma:
Application of a
New Multidisciplinary Policy Paradigm

by

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Abstract

In this dissertation, a comprehensive, integrated, multileveled prevention paradigm is proposed to evaluate and/or reform existing FASD policies. There is a variety of evidentiary sources available to policy makers, but there is increasing pressure to utilize more rigorous approaches to analyze the "complex evidence base". I consider the need for high quality evidence including research and non-research sources, as well as quantitative and qualitative approaches. Findings from my own research, as appropriate for each level's focus, are also discussed.

I begin with the tertiary prevention level which aims to provide individuals affected by FASD continuous interventions throughout their lives so they will "not commit" and can function in the community. However due to the secondary disabilities associated with FASD, these individuals are often found within the criminal justice system. I present a comparison of individuals diagnosed with FASD found within a serious and violent offender population with those who are not diagnosed. I highlight exemplar legal cases where FASD is considered. In addition, I discuss exemplar initiatives and programs addressing the management of affected individuals.

The secondary prevention level focuses on interventions to modify those environmental conditions that increase the possibility of maternal drinking. I present an extensive list of risk factors for FASD. Next I reveal four themes of intervention from the literature: screening tools, research, education, and legal strategies. With those in mind, I examine a high risk population using the existing literature on social determinants.

The goal of the primary prevention level is to modify the social and environmental conditions that increase the opportunities which create individuals affected by FASD. At this level, the evidence I bring to bear are data which juxtapose medical facility locations and recorded police contacts with intoxicated persons in the same area.

My findings suggest an integrated systems approach would be an effective way to identify, validate, implement, and evaluate current FASD policy and practices. By employing this tri-level prevention paradigm, it is possible to address the complexities of FASD, identify the gaps in knowledge and services, and discuss more promising policy and practical initiatives.

Keywords: fetal alcohol spectrum disorder; policy model; integrated systems approach; prevention

To Josh and Jorja,

my biggest distractions and

my greatest motivators

and

To Margaret, who never stopped believing…

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ADD	Attention Deficit Disorder
ARBD	Alcohol-related Birth Defects
ACCD	Affective and Cognitive Control Deficits
ADHD	Attention Deficit Hyperactivity Disorder
ARND	Alcohol-related Neurodevelopmental Disorder
BTC	Breaking the Cycle
BMI	Body Mass Index
CCO	Continuing Care Order
CD	Conduct Disorder
CHOICES	Changing High Risk Alcohol Use and Increasing Contraception Effectiveness Study
FAE	Fetal Alcohol Effects
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
FPS	Forensic Psychiatric Services
ICD	Impulse-control Disorder
ICF	International Classification of Functioning
ICOH	Internal Coalition Outcome Hierarchy
ISTA	Integrated Systems Theory Approach
MATID	Maternal, Alcohol, Tobacco and Illicit Drugs
MCFD	Minstry of Child and Family Development
ODD	Oppositional Defiant Disorder
PIRS	Police Information Systems Retrieval System
PFAS	Partial Fetal Alcohol Syndrome
PTSD	Post Traumatic Stress Disorder
SCP	Situational Crime Prevention
SD	Standard Deviation
SES	Socioeconomic Status
STARS	Start Taking Alcohol Risk Seriously
TGFD	Too Good for Drugs

Chapter 1.

Introduction: Background to the FASD Policy/Prevention Analysis

Fetal alcohol spectrum disorder (FASD) is a range of physical, biological, and neurological disabilities linked to prenatal exposure to alcohol. FASD is the most common preventable cause of mental disability. Recent changes to the name, FASD, incorporate the many levels of FASD which reflect the degree of disability and resultant behaviours. Although the major physical malformations and disabilities characteristic of FASD are well researched, the cycle of alcohol abuse including binge drinking amongst child-bearing women and FASD continues, largely unabated. In addition to the financial and emotional costs associated with FASD, it is linked as well to increased criminal activity and victimization (Fast, Conroy & Loock, 1999).

FASD has been viewed for the past 30 years as an epidemic in First Nation and Aboriginal communities in Canada. A vastly disproportionate number of Aboriginal youth are involved in the youth criminal justice system and custody, and this phenomenon continues into the adult population. So why, three decades later, have we not developed systematic policies to reduce, if not eliminate, the number of individuals affected by FASD?

This dissertation will present the major challenges with implementing FASD policies, starting with defining and measuring the problem. There is great discrepancy in the discussion of the prevalence of FASD in the literature. Some researchers do not distinguish between incidence and prevalence. As well, the confusion in terminology results in questionable data because it might not be explicit for a given specific population, period of time, or the group at risk for the condition.

Besides challenges with defining what the problem is, there are challenges with accurately measuring the problem. There needs to be a standardized protocol for

classifying cases, which raises the question: How are the cases ascertained? Although there are established approaches to studying the prevalence and patterns of FASD, fetal alcohol syndrome (FAS), alcohol-related birth defects (ARBD), and alcohol-related neurological disorders (ARND), these epidemiological studies are rare.

Next there are complications with diagnostic methods, as well as economic and accessibility constraints. Although the diagnostic criteria for FAS have remained relatively unchanged since the mid-1970s, there is no objective laboratory test, and a diagnosis of FAS requires confirmation of maternal alcohol use during pregnancy and/or around the time of birth. Because diagnosis is made on central nervous system dysfunction and facial morphology, it may be difficult to assess prior to the age of two years. Difficulties are also encountered by adolescence, when the FAS facial morphology becomes less distinctive and the individual's weight approaches the mean (Streissguth et al., 1994). Ethnic populations and growth due to age are two more factors that further complicate FASD assessments.

Besides the actual diagnostic criteria, a FAS diagnosis can be unreliable and biased because few clinicians are trained to recognize it. As well, clinicians are aware of the stigma attached to FAS which leads to a decreased likelihood of a FAS diagnosis in the official medical records. More funding needs to be provided to increase the number of accredited diagnostic specialists as well as, to supply the equipment necessary to make proper assessments; thereby making diagnosis more accessible. In addition, British Columbia has five different health regions consisting of urban, rural, remote, and Aboriginal areas, each having its own varying population with specific needs and required funding.

The proposed tri-level framework is the central theme of this dissertation. It will be used to highlight and address the deficiencies that emerge from existing policies in Canada, and more specifically, British Columbia. The second theme is to review policies and practices and to link these issues to the current treatment and management of individuals affected by FASD. Discussion is provided on more appropriate treatment of individuals affected by FASD that spares them from shame or guilt. As well "more promising" initiatives are presented, dealing with secondary disabilities that develop as the affected individual matures. Strategic plans that encompass all levels of government are necessary; however, community-based services appear to be more successful

because they are accessibile, conquering one of the major barriers to treatment and management initiatives.

The third theme presented in this dissertation is the demonstration of policy themes using a sample of serious and violent offenders with FASD. Literature indicates that individuals affected by FASD may experience mental health issues, substance abuse, disruptive school experiences, and employment difficulties, all leading to criminal behaviours if the appropriate support and services are not available (Morley, 2006). Therefore one would anticipate that individuals affected by FASD can be found in the criminal justice system. Access to The Study on Incarcerated Serious and Violent Young Offenders presents a unique opportunity to analyze the social factors that are consistent with individuals affected by FASD as well as predict future behaviours.

The fourth theme presented is, what can be learned policy-wise from the above review and case study examples? The proposed framework stresses the multi-levelled initiatives that deal with all aspects of the FASD problem. Initiatives need to be aimed at the individual with FASD, the high risk mother and women of child-bearing age, in general.

Therefore, the main objective is to elaborate a more complex and potentially valid policy model concerning FASD. To date, policy to address the needs of individuals with FASD and others potentially affected by it (e.g. mothers, the communities in which individuals with FASD live, and the agencies expected to provide related services) has been too narrowly focused, making such policy ineffective and difficult to develop. It will be argued that if this situation is to improve, a complex, multi-ministerial agency policy model is needed, one that (a) emphasizes early interventions designed to minimize the likelihood of FASD occurring, (b) provides subsequent systematic interventions throughout the developmental stages that FASD individuals experience, and (c) acknowledges the disabilities associated with FASD and subsequent problems with current policies in the criminal justice system. Before pursuing these thesis themes further, it is necessary to review the key policy analytic construct.

Policy Overview

What is Policy?

The intertwined concepts of policy making and policy analysis have a lengthy history of discussion and debate (Dunn, 2004). Most simply, policy has been defined as "anything a government chooses to do or not to do" (Dye, 1972, p. 2), but a more complex characterization is "a purposive course of action followed by an actor or a set of actors in dealing with a problem or matter of concern" (Anderson, 2000, p. 3). At a minimum, most researchers assert that policy involves selecting a choice among many alternatives. Milne (2006) elaborated this theme further, saying that policy "is best expressed as vision and goals, with associated strategic objectives, work plan and a program of activities, resources and leadership to achieve that choice" (p. 17).

Still, the policy process does not simply comprise chronological task choices and implementation; researchers have argued that policy actors do not typically create, choose, and implement policies systematically (Pal, 2006). Though the policy process may not always be systematic, it has been widely accepted that it occurs in stages; that is, these stages (agenda setting, policy formulation, decision-making, policy implementation, and policy evaluation) can be iterative and sometimes complex and confusing, with feedback loops (Pal, 2006).

The stage model of the policy process has several advantages. First, it promotes "a methodological heuristic: facilitating the understanding of the public policy process by breaking it into parts" (Howlett & Ramesh, 2003, p. 245). Each component and its relationship to components in the other stages of the cycle can then be investigated individually. Second, individual cases, as well as series of cases, can be examined within each stage of the process to increase the validity of the explanation of specific policies, especially complex ones. The latter are characterized by numerous components or variables often found in highly controversial policy areas such as in criminal justice and economics. Finally, the model stimulates visualization of the entire process (Howlett & Ramesh, 2003).

Policy Evolution

Howlett and Ramesh (2003) have asserted that there has been a movement away from a traditional linear interpretation of the policy cycle to a more nuanced perspective concerning the analysis and conceptualization of the public policy process. They claimed that this change reflected a late 20th century trend towards post-positivist methods of analysis in policy science where the policy process was conceptualized as a social phenomenon created by contingent and intricate processes (Hilgartner & Bosk, 1981). This change in conceptualization required appropriate methodology to accommodate subtle empirical complexities.

Cook (1985) was among the most prominent scholars who maintained that social problems and subsequent government policy responses were influenced by a complex range of factors. Robinson's (2004) Integrated Systems Theory Approach (ISTA) exemplified this policy model, which included underlying factors from multiple ministries, agencies, programs, and interest groups explicitly identified and then linked systematically in an interdependent decision-making nexus. Other complex models utilized extremely sophisticated mathematical and algorithmic logic based on tipping points and chaos theory. These models presumed that a policy intervention on a vector could change causal relations and outcomes (Pal, 2006).

Implementation of FASD Policy

FASD policies have historically focused narrowly on individuals with FASD whose antisocial behaviours resulted in social workers, educators, and youth and adult criminal justice officials responding to protect those with FASD and families and the community from them. By only focusing on the affected individual, programs were devised and administered that were insufficiently interconnected. For example, they did not adequately connect resource needs of FASD individuals, their families, and community institutions. Most importantly, there has been a definite lack of diagnostic services.

In Canada, FASD was primarily identified with Aboriginal and First Nations communities. Not surprisingly, it was within these communities that the narrow policy model approach to FASD failed. According to a Health Canada (2004) review, policy

typically focused on pregnant women and mothers who became isolated from their families and communities because of feelings of shame, guilt, and grief.

Most recently, most government ministries – federal, provincial, and territorial, along with First Nations and Aboriginal communities -- realized that FASD had to be addressed on multiple levels (individual, family, community and both, regionally and nationally) (Pal, 2006). It will be asserted that the ISTA model approach to treatment and management spares FASD individuals from the shame, guilt, and grief that has been an outcome of the individual-focused policy model. As well, once all the ISTA factors are clearly articulated, policy stakeholders will have a comprehensive understanding of specific program and case objectives. Also, based on program feedback, decision makers will be better informed regarding feasible initiative options. Ultimately, it is the broader FASD policies that benefit from the ISTA model approach.

Is FASD a "Wicked Problem"?

FASD is a persistent, stubborn, and deep-rooted problem that has exemplified what is known as a policy "wicked problem".[1] Roberts (2000) elaborated the conceptual policy framework of *wickedness*, a term that has also recently been applied to "broader social and economic problems"[2] related to issues such as FASD (Briggs, 2007). Regarding this "wicked problem" framework, Rittel and Webber (1973) postulated the following as "ten distinguishing problems that planners or policy makers should be aware of":

1. There is no definitive formulation of a wicked problem.
2. Wicked problems have no stopping rule.
3. Solutions to wicked problems are not true-or-false, but bad-or-good.

[1] The term *wicked problem* was coined by Rittel and Webber (1973) to highlight those problems that seem to be impervious to change, such as FASD.

[2] *Wicked* being that some problems are "resistant to traditional and linear solutions" and "different kinds of solutions are necessary and that even such problems may never be solved entirely" (Russell, 2011, p. 379).

4. There is no immediate and no ultimate test of a solution to a wicked problem.
5. Every solution to a wicked problem is a "one-shot operation"; because there is no opportunity to learn by trial-and-error, every attempt counts significantly.
6. Wicked problems do not have an enumerable (or an exhaustively describable) set of potential solutions, nor is there a well-described set of permissible operations that may be incorporated into the plan.
7. Every wicked problem is essentially unique.
8. Every wicked problem can be considered to be a symptom of another problem.
9. The existence of a discrepancy representing a wicked problem can be explained in numerous ways. The choice of explanation determines the nature of the problem's resolution.
10. The planner has no right to be wrong" (pp. 161-166).[3]

Typically policies that address wicked problems require a collaborative approach. In this thesis, this collaborative policy approach will be central to identifying, validating, implementing and evaluating current FASD policy and practices.

Since FASD, like most wicked problems, is an enormously complex social problem, it requires that policy development include multiple levels of government and from the community and FASD families and individuals affected by FASD. By utilizing an integrated tri-level paradigm,[4] which will be proposed in this dissertation, all levels of organizational services can fit into one of the three levels of prevention and support services more effectively. Specifically, this approach reduces major barriers to the necessary multiple services. As well, interested stakeholders can be identified and included in the decision-making process as well as incorporated into the implementation

[3] These were taken verbatim from the text but that the elaborations of each one were not included here.

[4] Tri-level paradigm includes initiatives directed to each of the prevention levels: affected individual, at risk women, and women of child-bearing age.

of services. In addition, this framework will demonstrate the importance of research synthesis in the policy analysis of complex models. First, it is important to discuss what can be considered effective or "good policy", generally and specifically, regarding FASD.

What is Good Policy?

A movement towards research evidence based policy and practice began in the 1970s, first, as "empirical based practice", then, to "evidence based practice". Currently, research evidence based policy is referred to as *best practices* or *practice guidelines* (Schuerman et al., 2002). Regardless of the specific terminology, there is a broad consensus that good policy should be linked to valid evidence, not just opinion or common sense (Bowen, Zwi, & Sainsbury, 2005). However, controversy still exists over the question: What is valid evidence? And what kinds of evidence make good policy?

Many question how good policy is, when it is based on poor or little data, as in the case of FASD. I will discuss the link between policy and evidence, more specifically the kinds of evidence, how evidence is obtained, and how it is used. A number of issues have arisen in relation to the suitability of evidence, particularly with the emergence of "good policy". These limitations of evidence will be discussed in relation to how and why they are important in the production of meaningful policy.

Types and Quality of Research Producing Evidence

It is assumed that "good policy" is created from "good evidence". Therefore, an understanding of the terminology of current data collection methods is required before the application to policy development can be made. In addition, the strengths and weakness of the methods need to be evaluated in order to select the "best evidence" for policy making.

The concept of *robustness* of evidence also has been utilized to describe this approach to improving policy construction and evolution. Additional terms common to *best evidence* include *credibility*, *generalisability*, *reliability*, *objectivity*, and *rootedness*, all of which address *robustness* (see Shaxson, 2005). All these concepts are central to systematic evidence gathering. In addition, more recently, there has been the assertion

that systematic research reviews require a minimum requirement of methodological rigour (Hammersley, 2005).

Within the social sciences, *research synthesis*,[5] *research review*, and *systematic review* are frequently interchanged terms; however, there are subtle differences in meaning for each of the terms (Cooper & Hedges, 2009). For example, while a research review is used in the original context of research synthesis, it also describes the process of assessing the quality of research (Cooper & Hedges, 2009). Since research syntheses consist of this evaluation of research, using *research synthesis* avoids confusion; however *systematic review* is used less frequently in the context of research evaluation, particularly in the social sciences, but still causes confusion. Research synthesis focuses on a particular set of literature review characteristics. The major advantage of the research synthesis is the primary focus and objective: to integrate results of empirical studies with the intent of creating generalizations as well as acknowledging limitations. As well, research synthesis draws attention to significant theories, evaluates the research described, presents and addresses conflicting literature, and suggests relevant directions for future research (Cooper & Hedges, 2009).

Meta-analysis is frequently used as a synonym for *research synthesis*; however, the formal meaning is "The statistical analysis of a large collection of analysis results from individual studies for the purpose of integrating the findings" (Glass, 1976, p. 3). In effect, this methodology involves sophisticated statistical analyses of research studies that employ research design, typically, with rigid "scientific" criteria. However, *meta-analysis* is not equivalent to integration or synthesis, which involves collective outcomes beyond the results of individual studies (Hoyle, 1993). Due to rigid scientific criteria, many researchers and policy makers believe that evidence derived from *meta-analysis* is valid, reliable, credible, and generalisable; hence, the best available evidence for policy development.

[5] I will use the term *research synthesis* throughout this dissertation.

The Use of Evidence

Regardless of the terminology, research synthesis attempts to incorporate all the data on one topic -- for example, the effectiveness of a program -- when multiple studies exist. There are strict rules for the standardization of study inclusion and exclusion which are based on certain criteria that facilitate “rigor, systematicity, and transparency” (Cooper & Hedges, 2009, p. 11). Research synthesis presents evidence in a neutral manner, decreasing the likelihood of bias or subjective perspective and increasing the reliability of the process. This method is intended to identify all the evidence, not only those studies overrepresented in the published research or those studies that are readily accessible, thereby ensuring validity (Cooper & Hedges, 2009; Sherman, 2003).

In addition, Hammersley (2005) states that research results should be presented to the public in the form of reviews of available literature as opposed to simply conclusions of individual studies. As well, Chalmers (2003) asserts that evidence based research should be the foundation for professional practice while opinion based decisions should be avoided (Shaxson, 2005).

Nevertheless, despite this movement to more systematic empirical policy research, many critics counter that this scientific methodology is misleading practice since actual policy has been very subjective and based on individual assessments of all relevant and available information. Furthermore, because little policy evidence is fully valid; decision makers, either those making policy or practitioners, need to critically evaluate the research assertions in the context of their own experience and background knowledge (Hammersley, 2005). In addition, it is inherently difficult to relate aggregated study findings to specific cases that rarely are identical. As well, conflicting evidence from alternate sources of information often complicates any simple policy inferences (Byrne, 2004).

In spite of these challenges in utilizing the research synthesis model for policy analysis, in the last 20 years, this approach has extended from psychology and education to other disciplines including medical sciences and social policy analysis

(Cooper & Hedges, 2009). For example, in 1992, the Cochrane Collaboration[6] on health policies expanded from a small international working group of individuals into "an internationally renowned initiative with 11,000 people contributing to its work, in more than ninety countries by 2006" (Cooper & Hedges, 2009, p. 10). The Cochrane Collaboration has become "the gold standard" for evaluating health care interventions. Similarly, the Campbell Collaboration[7] was developed in 2000 to develop extensive social policy analysis and models involving education, social welfare, and crime and justice themes (Cooper & Hedges, 2009).

Finding Evidence

A simple "searching" exercise for information on FASD, using the key words including *alcohol*, *pregnant*, *pregnancy*, *prenatal*, *FASD*, *FAS*, and *FAE*, demonstrates the lack of "gold standard" sources. Only 21 completed reviews in the Campbell Library are identified but they all involved only *alcohol* (Table 1.1). A search for *FASD*, *FAS*, or *FAE* did not produce any submissions including, title only, proposal, or reviews. However, the Cochrane Database generated four articles specific to FASD, 12 articles related to alcohol and pregnancy, and 22 articles on alcohol and behaviour in general.

Table 1.1. Completed Reviews Retrieved from the Campbell Library and Cochrane Database Using Specific Key Words.

Database	Key Words[a]	Study Focus
Campbell Library	Alcohol (21)	Drugs and drug courts (1)
		Sentencing (1)
		Interventions for substance abuse (3)
		Pregnant woman + interventions (3)
		Parent training (1)
		Children and adolescents behaviour (5)
		Adolescent pregnancy (1)

6 Retrieved May 2010 from http://www.cochrane.org/index.htm.

7 Retrieved May 2010 from http://www.campbellcollaboration.org/

Database	Key Words[a]	Study Focus
		Treatment/interventions dealing with aggression, sexual offenders, domestic violence, imprisonment, housing (6 total)
Cochrane Database	FASD (4) [b]	Skills/performance (3)*
		Diagnostics (1)**
	Alcohol + pregnant (pregnancy/ pregnancies) (2)	Support services (2)
	Alcohol + prenatal (10)	Assessment (1)
		Treatment (2)
		Intervention (4)
		Improving pregnancy outcomes (3)
	Alcohol + behaviour (22)	Alcohol + young people (4)
		Alcohol + driving (4)
		Alcohol + treatment/intervention (14)

[a] Numbers in brackets () indicate the number of articles found for each study focus.

[b] Numbers in brackets () indicate the number of individuals used in the study. For most of the reviews, the number of individuals involved was not easily attainable

* (*N* = 100, 65, 54, respectively)

** *N* = 81.

Badry and Bradshaw (2010) conducted a peer-reviewed literature search for *FASD* and *adults*, which used the University of Calgary online databases as well as more general searches on Google Scholar. A total of over 100 articles were recovered when using combinations of the following the key words: *FAS*, *FASD*, *FAE*, *fetal alcohol*, *adult*, *diagnosis,* and *Canada*. The articles were grouped into common themes including screening and referral, diagnosis, assessment tools and techniques, emerging issues, and types of evidence (e.g. conceptual, evidence-based, practice-based, and incidence/prevalence) (Badry & Bradshaw, 2010).

For this thesis, I also conducted a preliminary search in Google Scholar, using similar search words in conjunction with a key methodological term, which uncovered numerous related studies (Table 1.2). Using the term *alcohol consumption*, regardless of the specific methodological term (e.g. systematic review, meta-analysis, etc.), 264 articles were produced while 71 articles emerged when *FASD* was used. Most of the literature pertaining to *alcohol consumption* related to drinking patterns in general,

prevention and intervention; and birth outcomes along with developmental and neurological defects. When *FASD* was queried, intervention, treatment, and prevention; as well as developmental and neurological defects research emerged.

Table 1.2. Searches Obtained Using Google Search Engine.

Key Words	Focus
Alcohol consumption + pregnant + systematic review (where alcohol was the focus) (35)	FASD or associated malformations (4) Prevention (8) Intervention (10) Drinking patterns (6) Birth outcomes (7)
Alcohol consumption + pregnant + systematic review (where alcohol was not the focus) (109)	HIV/STD (5) Smoking (8) Smokeless tobacco (4) Drinking patterns (4) Birth outcomes (5) Developmental/neurological defects (1) Caffeine (2) Lead (1) Partner Violence (1) Intervention (2) Prevention (1) Health related (75)
Alcohol consumption + pregnant + meta-analysis (31)	Intervention (6) Prevention (5) Risk factors (6) Developmental/neurological defects (8) Birth outcomes (1) General health (2) Drinking patterns (3)
Alcohol consumption + pregnant + randomized controlled trials (20)	Smoking and alcohol (1) Alcohol abuse (2) Developmental/neurological defects (1) Birth outcomes (1) Intervention (4) Prevention (5) Treatment (6)
Alcohol consumption + pregnant + single randomized trial (0)	None found
Alcohol consumption + pregnant + observational study (49)	Alcohol consumption (15) Developmental/neurological defects (17) Birth outcomes (10) Prevention (5)

Key Words	Focus
	Intervention (1) Support services (1)
Alcohol consumption + pregnant + physiological study (0)	None found
Alcohol consumption + pregnant + clinical trial (20)	Alcohol consumption (3) Birth outcomes (6) Prevention (4) Intervention (6) Treatment (1)
FASD + systematic review (21)	Drinking Patterns (2) Policy (4) Interventions (4) Prevention (4) Prevalence (1) Birth Outcomes (1) Developmental/neurological defects (5)
FASD + meta-analysis (19)	Drinking patterns (1) Alcohol use/health (2) Intervention (5) Prevention (3) Developmental/neurological defects (6) Risk factors (1) Birth outcomes (1)
FASD + randomized controlled trials (15)	Developmental/neurological defects (2) Intervention (6) Prevention (5) Treatment (1) Substance abuse (1)
FASD + single randomized trial (0)	None found
FASD + observational studies (9)	Developmental/neurological defects (2) Support services (1) Prevention (1) Treatment (2) Alcohol consumption (3)
FASD + physiological trial/study (1)	Ethanol exposure (1)
FASD + clinical trial (6)	Prevention (3) Intervention (2) Treatment (1)

Note. Bracket (*N*) indicates the number of articles obtained using key words.

It was evident that certain collection methods favored certain topics of research. For example, observational studies were associated with a large number of studies (17)

on developmental and neurological defects, while conversely, randomized controlled trials only revealed one study. Results from this simple query clearly demonstrate that search criteria can bias the literature retrieved. As well, it is evident that multiple methods are needed to obtain a clear picture of the specific issues being queried.

Limitations to this literature collection method include recall and precision. *Recall* refers to the percentage of relevant documents obtained by the search criteria, compared to the total in the collection that should be retrieved (White, 2009). *Precision* is "the ratio of documents retrieved and judged relevant to all those actually retrieved" (White, 2009, p. 56). In this case, a comprehensive search (or high recall) was the objective; therefore, it was expected that additional time would be required to sift through irrelevant documents and duplicated literature (White, 2009). Many of the articles were located multiple times due to the overlap in key words that generated the queries. For example, many articles used *systematic review* as well as *meta-analysis* as key words and therefore were retrieved by each query. As well, some articles were associated with randomized controlled trials as well as clinical trials; therefore, duplication occurred. However, this pain staking process ensured that no significant papers were undetected by the search query. A search of academic databases (e.g., MEDLINE, EBSCO) produced most of the above articles (ensuring a high recall) except for non-academic literature, known as "gray literature"[8] which was only attainable by non-academic databases (e.g., Google Scholar). In addition, it appeared that this overlap and repetition of search terms ensured that there was no bias in the literature retrieved by the queries (White, 2009).

These general inquires, which are frequently conducted on search engines using specific terms, generate a significant amount of *fugitive literature* or *grey literature*, which is believed to be worthy of investigation by lay people and possibly decision makers (Rothstein & Hopewell, 2009; Sechrest, White, & Brown, 1979). In some cases, the research discovered by these simple queries, may be the only source of information

[8] *Grey literature* or *fugitive literature* consists of "government reports, dissertations and master's theses, conference papers, technical documents and other literature that is difficult to obtain" (Petrosino, Boruch, Soydan, Duggan, & Sanchez-Meca, 2001, p. 17)

available and used to make policy decisions. Grey literature searches may identify "studies in progress [and] recently published studies not yet referenced in databases" (Benzies, Premji, Hayden, & Serrett, 2006, p. 58). In addition, "clinical wisdom" regarding treatments and interventions may be supported by grey literature, which may be based partially on theory, research, and/or trial-and-error methods (Benzies et al., 2006). Others, however do not consider grey literature to be scientific evidence and believe that "unpublished studies are of lesser quality" because they have not been peer reviewed (Petrosino et al., 2001, p. 17). As well, some deem unpublished studies as lacking the standards for presentation of the information and referencing of sources (Benzies et al., 2006).

The small number of academic studies specific to FASD or even alcohol in general, obtained through the Campbell and Cochrane search databases (see Table 1.1), might lead one to question whether the breadth and depth of all the available research was captured. In order to understand the potential and thoroughness of using fugitive literature, I conducted an exploratory investigation using a number of government reports obtained through the Google Scholar search. These sources summarized the current state of evidence on FASD using systematic review type retrieval and standardization methods, although the sources are not formally considered systematic reviews. Hence, I clearly demonstrate the need, and make a strong argument for using fugitive literature as a source of evidence for decision-making.

Basford et al. (2004) conducted a thorough review of the sources of the evidence, particularly, identification tools for FASD and the prevalence of FASD (Table 1.3). As well, Gray and Henderson (2006) reviewed *alcohol consumption* and *birth outcomes* (Table 1.4). These reviews included all relevant articles from the Campbell and Cochrane databases, as well as grey literature that presented important contextual information. In addition, concerns regarding methodology and limitations were identified for each study.

Table 1.3. Grey Literature Search Identified "Systematic Reviews" for Diagnostic and Screening Tools and FASD Prevalence (Modified from Basford et al., 2004).

Topic	Number of Studies	Research Focus or Population concerns
Identification tools for FASD - diagnosis	3 studies	Facial anomalies (*N* = 293) Facial phenotypes (*N* = 194) 4-Digit code (*N* = 445)

Topic	Number of Studies	Research Focus or Population concerns
Identification tools for FASD - screening	9 studies	Tweak (*N* = 1165), (*N* = 4743) T-ACE (*N* = 971), (*N* = 1420), (*N* = 350) MAST (*N* = 238) CAGE (*N* = 196) Tweak/T-ACE/MAST/CAGE (*N* = 2717) AUDIT (*N* = 350)
Birth prevalence	11 studies	Different populations, data source, study period
Prevalence of FASD	4 studies	Different population, age range (0-14 years)

Note. (*N*) indicates the number of individuals in the study. Some of the individuals were used in multiple studies. Most studies stress the findings of systematic reviews and do not explain fully the methods (Basford, *et al.,* 2004; Waller, Naidoo & Thom, 2002).

Gray and Henderson (2006) conducted a comprehensive search regarding alcohol and birth outcomes. Research was categorized based on alcohol consumption which ranged from *exposure*, *low-to-moderate consumption*, to *binge drinking* (Table 1.4). The methods of included research consisted of control studies, case studies, with the majority of the research utilizing cohort studies. Again, most of these studies would be deemed grey literature.

Table 1.4. Grey Literature Search Identified "Systematic Reviews" for Alcohol Consumption and Birth Outcomes.

Birth Outcome	Alcohol Consumption	Studies	Particulars
Spontaneous abortion	Low-to-moderate alcohol consumption	7 studies	2 case control studies, 5 cohort studies
Stillbirth	Low-to-moderate alcohol consumption	5 studies	2 case control studies, 3 cohort studies
Intrauterine growth restriction	Low-to-moderate alcohol consumption	7 studies	2 case control studies, 5 cohort studies
Birth weight	Alcohol consumption	20 studies (ranging from 412 to 40,445 persons)	All cohort studies
Preterm birth	Low-to-moderate alcohol consumption	16 studies met inclusion criteria but 2 case control studies were deemed poor quality	All cohort studies
Malformations	Low-to-moderate alcohol consumption	6 studies	All cohort studies
Postnatal growth	Alcohol exposure	2 studies	Longitudinal studies
Head circumference and length at birth	Low-to-moderate alcohol	5 studies	1 – birth length 1 – head

Birth Outcome	Alcohol Consumption	Studies	Particulars
	consumption		3 – both
Neurodevelopmental outcomes	Low-to-moderate alcohol consumption	7 studies	1 – outcome at birth 6 – longer term
Birth weight, gestational age and growth	Binge drinking	7 studies	
Birth defects	Binge drinking	3 studies	
Neurodevelopmental outcomes	Binge drinking	4 studies	

Note. Some of the studies were found in multiple categories – e.g., 11 articles on binge drinking when broken into component parts looked like 14 articles. *Modified from Gray and Henderson (2006).*

Credible information can be found within the grey literature which contains studies using qualitative as opposed to quantitative methods. Qualitative research is well suited for the social sciences, particularly for understanding a phenomenon, "because it generates a rich description of both local contexts and individual subjective experiences" (Silverstein, Auerbach & Levant, 2006, p. 351). Although qualitative methods may be applied on a descriptive level, themes can be codified and hence used as a tool for quality assessment (Kazdin, 2008; Malterud, 2001). Qualitative methods allow for a thorough study of individuals in a "scientifically rigorous way" and seem to naturally bridge the gap between research and practice (Kazdin, 2008, p. 157).

Qualitative methods are "systematic, replicable, and cumulative" and meet the "desiderata of science" (Kazdin, 2008, p. 153). The procedure is based on precise sampling strategies, systematic data analysis, and a commitment to examining counter explanations; hence, these studies should be transparent, communicable, and coherent (Green & Britten, 1998; Rubin & Rubin, 1995). The goal of qualitative methods is to construct transferable theories or frameworks that can be applied to different research samples, even though the specifics will not be applicable (Silverstein et al., 2006). The accuracy of conclusions obtained by qualitative methods can be strengthened by using data obtained from multiple means to analysis of a single phenomenon, referred to as *triangulation* (Denzin, 1970). For example, when qualitative and quantitative methods complement each other, the validity of clinical evidence is strengthened (Malterud, 2001). As well, analysis of a phenomenon is completed when saturation is reached. Saturation occurs when the addition of samples no longer provides new information; it just confirms existing knowledge (Mays, Pope, & Popay, 2005; Silverstein & Auerbach, 2007, p. 30). Regardless of the methodology, scientific quality cannot be guaranteed:

The crucial component is how the information is organized and analyzed; and how the subsequent knowledge is presented (Malterud, 2001).

Many researchers believe that systematic reviews can benefit from the inclusion of qualitative studies; however, the addition of this information creates methodological challenges (Lucas, Arai, Baird, Law, & Roberts, 2007). State-of-the-evidence reviews are broader than traditional systematic reviews and may include published and unpublished research and non-research literature (Benzies et al., 2006) As well, research synthesis currently has "less developed methods for synthesizing qualitative research evidence, though there is important work being undertaken to redress this imbalance" (Davies, 2004, p. 3).

In summary, there is a variety of "evidence" sources available to policy makers, but there is increasing pressure to utilize more systematic approaches to analyze the "complex evidence base" (Mays et al., 2005). Policy makers must be accountable for complicated questions regarding the "perceived" problem, proposed interventions, discrepancy in impact, cost-effectiveness, and acceptability (Mays et al., 2005). Therefore "Cochrane-style reviews" are not sufficient. High-quality evidence consisting of academic and non-academic sources and both qualitative and quantitative research findings is necessary (Mays et al., 2005). New approaches such as best evidence synthesis, thematic analysis, realist synthesis, qualitative cross-case analysis, content analysis, and Bayesian meta-analysis attempt to address these inadequacies (Mays et al., 2005; Pawson, Greenhalgh, Harvey, & Walshe, 2004; Slavin, 2002). It is within the spirit of "new approaches" that I propose the comprehensive, integrated, multilevel paradigm[9] that utilizes available data sources to examine current social problems, specifically FASD policy and procedures. Although the paradigm presented in this dissertation utilizes an existing tri-level prevention model; the uniqueness and strength of

[9] Thomas Kuhn defined paradigm as "universally recognized scientific achievements that, for a time, provide model problems and solutions for a communit of practitioners" (1996, p. 10). Building on these principles, Handa (1986) identified the basic components of a paradigm within the context of social sciences and focused on the social circumstances that precipitated the shift and the subsequent effects of the shift on social institutions, such as education. The overall goal of the paradigm shift was the modification of an individual's perception of reality.

this research lies within the advancement of the model achieved by incorporating Robinson's integrated systems theory approach within each of the levels.

Chapter Organization

So far, I discussed what is believed to be good policy, and presented an overview of the issues involved in evidence use and gathering in relation to the movement towards evidence-based policy or decision-making. I demonstrated the lack of empirical data regarding FASD policy implications and introduced FASD as a "wicked problem", substantiating the need to develop a more appropriate policy framework.

Chapter 2 introduces Fetal Alcohol Spectrum Disorder (FASD) as the case example for this dissertation. I begin with a discussion of the teratogenic effects of alcohol, the diagnosis and criteria of FASD, and the emergence and abnormalities of FASD. I present the integrated systems models as well as consider multi-leveled government and community collaborations. I examine present issues and controversies in policy dynamics. I discuss the current state of research leading into the proposed policy paradigm, three levels of prevention: primary, secondary and tertiary.

In Chapter 3, I outline the methodological approaches and rationale for data collection and analysis for each of the prevention levels. I explain Robinson's model, an integrated systems theory approach, in relation to FASD and in particular to how it can affect and improved the policy paradigm.

Chapter 4 introduces the tertiary level of prevention considerations and builds on the discussion of FASD presented in Chapter 2. Statistical analysis on data requested from the Study on Serious and Violent Incarcerated Youth will be integrated within the existing literature. I highlight the implications of secondary disabilities, the link to criminality, and the rational choice debate. I stress the need to utilize a comprehensive, integrated, multileveled paradigm such as the one provided in this dissertation to evaluate existing FASD policies.

I deliver a unique policy framework that considers the multitude of factors that affect an individual with FASD as well as the interrelated issues and barriers to acquiring services. Within this framework, the plethora of identified factors are substantiated by a

preliminary qualitative analysis of legal cases involving individuals affected by FASD obtained from the CanLII database. By organizing the existing knowledge into the three prevention levels, I clearly illustrate the complexity of the issue in an understandable model which can easily adapt to multi-ministry and multi-agency collaborations. In addition, I critique the B.C. FASD Strategy using the developed framework presented in this dissertation.

Chapter 5 includes a discussion of the secondary level of prevention. The majority of this chapter will entail a literature review of articles on high risk women, including an exploration of the protective factors for FASD that focus on maternal predisposition, an overview of possible interactions between risk and protective factors, as well as a manipulation of maternal factors regarding preventative policies and practices.

Chapter 6 offers a detailed analysis of the available data and current policy implications for the primary level of prevention. I begin with the social construct of FASD, a discussion of prevalence and incidence studies, and a critique of common approaches to the epidemiological study of FASD. As well, I present locations of available medical services within British Columbia (B.C.) juxtaposed with female alcohol consumption rates, thus demonstrating the disjuncture in services.

For each of the above prevention levels (Chapters 4 to 6), I demonstrate the disjuncture between the research findings and current policy. In addition, I elaborate on the gaps in knowledge, identify the key roles of actors in the system and discuss the collaboration of multi-ministry and multi-agency service providers.

In the final chapter (Chapter 7), I summarize the findings of the dissertation, provide insight as to why the problem of FASD has not been solved, and revisit the "wicked problem" perspective. I conclude with a discussion of recommendations and future directions that address the improved ways to approach public health concerns to create "more appropriate" policy and practices.

Chapter 2.

Introduction to FASD

In this chapter, I begin with an in-depth description of fetal alcohol spectrum disorder including the historical review of teratogenic effects of alcohol, the definitions and characteristics, the emergence of abnormalities, and the diagnosis and criteria of FASD. Having reviewed the causes, outcomes, and widespread and devastating effects of FASD, I move to a discussion of the proposed tri-level approach to the prevention of this condition. I will conclude with a discussion on policy implications and the need for community collaboration.

Understanding Teratogenic Effects of Alcohol – Historical Overview

Historical Review

For hundreds of years, alcohol has been suspected as a teratogenic agent. The literature contains numerous warnings against alcohol use during pregnancy. For example, Aristotle was quoted as saying that "foolish, drunken, or hare-brain women, for the most part bring forth children like unto themselves, *morosos et languidos*" (Mattson & Riley, 1998, p. 279). The early Greeks in Carthage and Sparta prohibited drinking on the wedding night for "fear of begetting a damaged child" (Haggard & Jellinek, 1942).

A British Parliament report dated in the 1700s, described children of alcoholic mothers as having a "starved, shriveled and imperfect look" (Jones & Smith, 1973). During the first half of the 18th century, known as the "gin epidemic", English physicians warned women against alcohol consumption during pregnancy. Doctors claimed that maternal drinking was the cause of "weak, feeble, and distempered children" (Mattson & Riley, 1998, p. 279).

In 1899, Sullivan (1899) discovered a higher proportion of mortality and morbidity in children of female drunkards in the Liverpool jail compared to those of non-alcoholic relatives. Following this 1899 study, there was little research on the teratogenic effects of alcohol in humans for the next 70 years (Streissguth, 1978). During this time, research concentrated on the premise that genetic damage was caused by alcoholism and that many problems of children of alcoholics came from the unstable environments created by alcoholic parents (Warner & Rosett, 1975; Streissguth, 1976).

In the post-prohibition medical community; the belief that consumed alcohol during pregnancy could cause harm to the developing fetus was dismissed as "moralism" (Warner & Rosett, 1975). It was believed that the damaging effects noticed in the children of alcoholic women were the result of legitimate factors that would account for both damage in children and the alcohol problem. It was not until the late 1960s and early 1970s that awareness regarding the harmful effects of alcohol re-emerged (Mattson & Riley, 1998).

In 1968, Lemonine, Harrousseau, Borteyru, and Menoet (1968) published an article in a French medical journal on a malformation syndrome found in the children of female alcoholics. This original research received little attention, probably because it was not publicized in the English literature. The cohort studied consisted of 69 families including 127 children and 5 mothers. However, these 5 mothers originally gave birth to adversely affected children, but subsequently gave birth to one or more healthy offspring after refraining from alcohol consumption during pregnancy.

In addition, this French report alluded to animal research dating back to the early 1900s which focused on the etiology and mechanisms of ethanol embryopathy (Koren & Navioz, 2003[10]). Exposing female mammals to high levels of alcohol resulted in harmful effects to mainly the first and second generations; the third to fifth generations of offspring were reported to be "more resistant and physically stronger than the controls" (Koren & Navioz, 2003, p. 131). These observations provided evidence in favour of

[10] Koren and Navioz (2003) was an English translation of a summary of the original work by Lemoine et al., (1968).

pharmacogentic mechanisms of ethanol embryopathy. In 1910, this report had provided a foundation for ethanol embryopathy and alluded to new experimental lines of research (Koren & Navioz, 2003). However, this research was ignored until 1973, when Seattle dysmorphologists documented analogous effects (Jones, Smith, Ulleland, & Streissguth, 1973).

Another study that received little acclaim was by Ulleland (1972) who first reported a failure to thrive and delayed development in offspring of alcoholic mothers. However, these observations may have been perceived as being attributed to the environment provided by the mother rather than to maternal drinking and, therefore, not worthy of academic recognition (Streissguth, 1978).

1970s to Present

In 1973, Jones et al. (1973) coined the term *fetal alcohol syndrome*[11] *(FAS).* Their paper described eight children who displayed similar abnormalities, including prenatal and postnatal growth deficiency, in addition to "short papebral fissures, epicanthic folds, ear anomalies, maxillary hypoplasia, minor joint and limb anomalies, and cardiac defects, and mental retardation" (Streissguth, 1983, p. 150). In 1976, Majewski et al. (1976) introduced the phrase *alcohol embryopathy* to describe children affected by maternal drinking during pregnancy.

Warner and Rosett (1975) completed a review of the historical prohibitions on drinking during pregnancy. In addition, a complete list of FAS characteristics and corresponding proportions of patients exhibiting each were compiled in 1976 (Hanson, Jones & Smith, 1976; Majewski et al., 1976). Ever since, research on the effects of prenatal alcohol exposure has continued to expand, resulting in the identification of a range of outcomes including miscarriages, stillbirths, spontaneous abortions, malformations, and lower birth weights, with more current research focusing on

[11] FAS refers to the original term and those individuals who display the visible deformities of the disease; whereas, FASD is a recent term applied to all the alcohol-related deficiencies that result from prenatal alcohol exposure.

behavioural outcomes (Streissguth et al., 1986; Testa, Quiegley, & Das Eiden, 2003). Behavioural differences have been observable almost immediately after birth, including weak sucking from neonates, increased tremulousness and fine motor uncoordination, decreased activity levels, and poor performance on operant conditioning tasks (Landesman-Dwyer, Keller & Streissguth, 1978; Little, 1977; Ouellette, Rosett, Rosman & Weiner, 1977).

FASD Definitions and Characteristics

It is well known that alcohol, a teratogenic agent, can produce a range of disabilities or birth outcomes. In the late 1990s, the term *fetal alcohol spectrum disorder* (FASD) emerged in the literature. Although this syndrome, caused by maternal drinking, is known to impact the brain, it has been blamed for affecting physical growth, development, temperament, learning, intelligence, cognitive ability, behaviour, memory, hyperactivity, and stress tolerance (Jones, Smith, Ulleland, & Streissguth, 1973; Streissguth, 1997).

FASD is a broad term that comprises a number of diagnoses describing the range of outcomes of prenatal alcohol exposure, extending from full FAS through to milder forms that affect physique, learning, and behaviour (O'Leary, 2004). The milder effects are termed *alcohol related neurodevelopmental disorders* (ARND) and *fetal alcohol effects* (FAE) or *partial FAS* (pFAS). Besides ARND, teratogenic effects of alcohol can result in alcohol-related birth defects (ARBD) characterized by physical anomalies. Both categories, ARND and ARBD, require confirmation of maternal alcohol exposure (O'Leary, 2004). There are numerous common appearances of ARBD. Maternal drinking during pregnancy may result in damage to a number of organ structures including the cardiac, skeletal, renal, ocular, and auditory systems (Stratton et al., 1996). In 2005, the Canadian Medical Association published national guidelines for diagnosis of FAS, pFAS, and ARND (Chudley et al., 2005).

Since the initial description of fetal alcohol syndrome (FAS), hundreds of studies of the children of alcoholic women have appeared including reports of a plethora of abnormal responses and delayed behaviours observed in neonates who were exposed to varying amounts of alcohol during gestation. Research has indicated that children

with FASD display intellectual deficits (Coles et al., 1991; Nanson & Hiscock, 1990), and their average IQs fall within the borderline range (Jones et al., 1973; Mattson, Riley, Gramling, Delis, & Jones, 1997; Russell, Czarnecki, Cowan, McPherson, & Mudar, 1991; Streissguth et al., 1991). Generally, FAS children performed less proficiently than controls on a wide range of tasks including those assessing information processing (Jacobson, 1998; Jacobson et al., 1993), number processing (Kopera-Frye, Dehaene, & Streissguth, 1996), visual-spatial reasoning (Carmichael Olsen, Feldman, Streissguth, Sampson, & Bookstein, 1998; Gray & Streissguth, 1990; Uecker & Nadel, 1996), auditory memory (Carmichael Olsen, Feldman, Streissguth, & Gonzalez, 1992; Gray & Streissguth, 1990), visual memory (Uecker & Nadel, 1996), spatial memory (Streissguth, Sampson, Carmichael Olsen, et al., 1994), verbal learning and memory (Mattson, Riley, Delis, Stern & Jones, 1996), and motor function (Chandler, Richardson, Gallagher, & Day, 1996; Roebuck, Mattson, & Riley, 1999).

Numerous researchers have also noted deficits in language skills (Abel, 1990; Abkarian, 1992), particularly word comprehension (Conroy, 1990; Gray & Streissguth, 1990), naming ability (Mattson, et al., 1997), articulation (Becker, Warr-Leeper & Leeper, 1990), and expressive and receptive language skills (Jansen, Nanson, & Block, 1995). On academic tests, alcohol-affected children tended to achieve lower scores on arithmetic tests, reading, and spelling, than on other tests, as well as having impaired ability on tests measuring attention (Carmichael-Olson et al., 1998; Coles et al., 1991; Coles et al., 1997; Goldschmidt, Richardson, Stoffer, Geva, & Day, 1996; Jacobson et al., 1993; Mattson, Goodman, Caine, Delis, & Riley, 1999; Streissguth et al., 1991).

Studies have indicated FAS children have lower executive functioning, or the ability to perform tasks that require planning, analyzing, and devising a strategy, executing it, and modifying it as it progresses (Coles et al., 1997; Kodituwakku, 2009; Kodituwakku, Handmaker, Cutler, Weathersby, & Handmaker, 1995; Mattson et al., 1999; Rasmussen, 2005). Streissguth et al. (1986) reported slower reaction times on vigilance tasks. In addition, researchers suggest that children with FASD are “slow learners”, who become “spacey” during tasks and frequently make omission errors (Kodituwakku, Kalberg & May, 2001).

Cognitive processes (e.g., IQ, language, executive functioning, academic skills) are based on a biological foundation composed of chemical reactions between various

cells and brain functions: If the foundation is healthy, everything built upon it is healthy; if there is dysfunction in the underlying layers (cells and organs), then there will be dysfunction in the upper levels. Psychopathy and ADHD, for example, are related to chemical and biological dysfunction of the brain which, in turn, can be exhibited in behaviours that have been deemed criminal.

Alcohol use during pregnancy in animal studies as well as human research have revealed hyperactivity, difficulties with response inhibition, attention deficits, poor habituation, poor coordination, and poor regulation (Mattson & Riley, 1998; Riley, 1990; Whaley, O'Connor & Gunderson, 2001).

Recently, research has focused on atypical behaviours in the FASD population (Coles et al., 1997; Streissguth, Bookstein, Barr, Press, & Sampson, 1998). Accumulating literature reiterates that FASD children tend to display a cluster of behaviour problems including impulsivity, disorganization, short-term memory problems, and difficulty in understanding subtle social cues (Kelly, Day, & Streissguth, 2000; Streissguth et al. 1998). In addition, alcohol-exposed children exhibit significantly more behavioural problems than non-exposed peers, specifically in the realm of social deficits (Kelly et al., 2000; Kodituwakku et al., 2001; Streissguth et al., 1998). These difficulties include a lack of understanding of social consequences of behaviour and inappropriate interactions. These behavioural problems overlap with poor executive functioning and have been referred to by some researchers as "dysexecutive syndrome" (Baddeley, Wilson, & Kipelman, 2002; Wilson, Alderman, Burgess, Emslie, & Evans, 1996). Morgan and Lilienfeld (2000) describe *executive function* as

> an umbrella term that refers to the cognitive processes that allow for future, goal oriented behavior. It is broadly defined as comprising the abilities needed to achieve and maintain a problem-solving set and includes such processes as planning, organizational skills, selective attention and inhibitory control, and optimal cognitive set maintenance. (p. 114)

Enns, Reddon, Das, and Boukos (2007) outline the way that executive function is linked to antisocial behaviour and suggest that there are three units of the brain identified by Luria (1973) that are linked to executive function.

The brain stem, specifically the medial regions of the hemispheres and the diencephalons, is the first unit and is responsible for arousal and attention (Enns et al., 2007). The parietal, occipital, and temporal regions of the brain form the second unit, which is responsible for coding information in an instantaneous or consecutive manner (Enns et al., 2007). The frontal and prefrontal regions of the brain, together considered the third unit, are closely associated with executive functions and are responsible for planning behaviour (Enns et al., 2007). Depending on the timing and amount of prenatal alcohol exposure, these regions, if damaged, will have differing effects on the individual that will result in the varying subcategories of FASD.

Furthermore, Enns et al. (2007) also suggest that persistent antisocial behaviours "originate in neurodevelopmental processes early in life and developmental risks may be heightened by interactions in high risk social environments" (p. 44). For example, individuals born with FASD continue to live with FASD and engage in anti-social behaviours during their entire lives. Enns et al. (2007) believe that deficits in verbal regulation and management of individual behaviour are essential in delinquent acts that persist through the life course. Enns et al. also made reference to a sample population with ADHD, a population which shares similar features with FAS/FASD.

The deficiency in executive functioning is exactly where individuals affected with FASD run into difficulties in their ability to, for example, be eligible for certain government services. The government provides services based on testing that shows an individual IQ of 70, the standardized level for a label of mentally challenged. A fairer and more feasible test for determining FASD independence would be one that measured the performance level of executive functioning, such as the Das-Naglieri Cognitive Assessment System. Basing the need for social services on IQ, and not on performance, has been proven to be inaccurate in measuring competency (Naglieri & Das, 1997).

FASD Developmental and Behavioural Abnormalities

Today the developmental and behavioural abnormalities associated with an FASD affected individual are well known, but the specific biological mechanisms that result in these abnormalities are complex and unfamiliar. Table 2.2 summarizes some of

the major deficiencies and the biological mechanisms associated with them. Research on prenatal ethanol exposure has concentrated on central nervous system development, generation of hippocampal long-term potentiation, motor performance, electrophysiological and neurochemical deficits, learning, memory, and behaviour inhibitions and has utilized a number of test subjects including humans, rats, mice, and guinea pigs (Table 2.1).

Table 2.1 Major Deficiencies of FASD Abnormalities and the Biological Mechanisms.

Deficiency (Model)	**Biological Mechanism**
<u>Central Nervous System Development (Human)</u> The mechanism of developmental neurotoxicity of ethanol is partly due to the effect on L1 cell adhesion molecules (Charness, 2013; Bearer, 2001)	Abnormal neurite outgrowth of cerebral cortex neurons projecting to the corpus callosum Enlarged ventricles/hydrocephalus Ocular deficiencies include nystagmus, ptosis, optic nerve hypoplasia (abnormal axon outgrowth of retinal ganglion cells), and retinal vessel tortuosity Hypoplasia of anterior vermis of cerebellum Abnormal growth of axons from dentate gyrus Abnormal migration of corticospinal neurons (Charness, 2013; Bearer, 2001)
<u>Generation of Hippocampal Long-term Potentiation and Learning (Mice)</u> Neurochemical alterations contributing to the hippocampal synaptic plasticity and behavioural deficits were observed in prenatal ethanol-exposed offspring (Savage, Becher, de la Torre & Sutherland, 2002). Ethanol produces deficits in activity dependent potentiation in glutamate release via a reduction in a PLC-β1→PKCβII/ϵ→GAP-43 phosphorylation signaling cascade, then one questions whether the neurotransmitter receptor regulation of this signaling cascade may contribute to this deficit (Savage et al, 2002). Increasing evidence confirms the involvement of hippocampal long-term potentiation (Jia et al., 1998; Lu et al., 1997; O'Leary & O'Connor, 1998) and	Queen, Sanchez, Lopez, Paxton, & Savage (2003) examined the impact of prenatal ethanol exposure on agonist-stimulated phosphoinositide (PI) hydrolysis. Muscarinic cholinergic receptor-stimulated PI hydrolysis was not affected by prenatal ethanol exposure. However metaboltropic glutamate receptor (mGluR)-stimulated PI hydrolysis was marked reduced in adult offspring whose mothers' mean peak blood ethanol concentration during pregnancy was 39/mg/dl (Queen et al., 1993). mGluRs functionally couple through the $G\alpha_q$ and $G\alpha_{11}$ G-proteins isoforms (Bristol & Rhee, 1994) to PLC-β1 via a pertussis toxin-insensitive mechanism. Activation of this system by nonselective group mGluRs agonsists increases glutamate release (Herrero, Miras-Portugal & Sanchez-Prieto, 1992). One study reported that the relatively selective $mGluR_5$ agonist 2-cholor-5-hydroxypheylglycine (CHPG) (Doherty, Palmer,

Deficiency (Model)	Biological Mechanism
learning (Lu et al., 1997).	Henley, Collinridge, & Jane, 1997) increases electrically evoked D-ASP release from hippocampal slices (Savage et al., 2001). Galindo et al. (2004) indicated that prenatal exposure to moderate quantities of ethanol reduces $mGluR_5$ expression in the dentate gyrus of adult offspring. Although the subcellular site(s) for reduced $mGluR_5$ expression could not be detected, the quantitatively similar effects of prenatal ethanol exposure on $mGluR_5$ agonist stimulation of presynaptically localized GAP-43 phosphorylation and CHPG potentiation of evoked D-ASP release suggest that the presynaptic
<u>Generation of Hippocampal Long-term Potentiation (LTP) and Learning (Rats)</u>	LTP deficits have been identified in adult offspring of rat dams who consumed ethanol during pregnancy (Swartzwelder, Farr, Wilson, & Savage, 1988). In addition, prenatal ethanol exposure has been reported to have multiple effects on glutamatergic signaling in the brain, including decreased affinity of hippocampal NMDA receptors for binding glutamate (Farr, Montao, Paxton & Savage, 1988a), decreased hippocampal kainite receptor number (Farr, Montao, Paxton & Savage, 1988b), and deficits in trans (1S, 3R)-1-amino-1,3-cyclopentanedicarboxylic acid (ACPD)-stimulated mGluR activation of phosphoinositide hydrolysis (Queen et al., 1993). These changes are thought, in part, to explain the LTP deficits observed in fetal alcohol rat hippocampal formation and may contribute to glutamate receptor antagonism (Morris, 1989). For example, prenatal ethanol-exposed rats exhibit performance deficits in spatial navigation tasks and in one-trial fear conditioned responses (Sutherland, McDonald & Savage, 1997).
<u>Motor Performance (Rats)</u> Ethanol-induced motor deficits may reflect damage to the cerebellum, given the role the role that the cerebellum plays in motor functioning (Ito, 1984). Thomas, Goodlett and West (1998) confirmed the presence of windows of vulnerability of Purkinje cells to neurotoxin effects of binge ethanol treatment, and demonstrated that both the behavioural and neuroanatomical consequences of binge exposure depend on the developmental timing	Relatively sharp window of temporal vulnerability to alcohol-induced reductions in cerebellar Purkinje cell density during the early postnatal brain growth spurt (Thomas et al., 1998). Thomas et al., (1998) reported that two consecutive days of binge-like alcohol before postnatal day (PD) 7 significantly reduced the density of Purkinje cell profiles in the cerebellar vermis, whereas similar exposure beginning on or after PD 7 had no significant effect. However, Thomas et al. (1998) demonstrated that ethanol treatment on PD 8/9 does reduce Purkinje cell number, indicating that

Deficiency (Model)	Biological Mechanism
of the exposure.	the Purkinje cells are still vulnerable to ethanol-induced cell loss even after PD 7.
<u>Electophysiological and Neurochemical Deficits (Rats)</u> Sutherland, McDonald & Savage (2000) observed a number of electrophysiological and neurochemical deficits in rat offspring whose mothers consumed moderate quantities of ethanol throughout gestation. FAE rats had problems in the acquisition of new place memory.	A significant decrease in both field excitatory postsynaptic potentials and population spikes' capacity to elicit long-term potentiation (LTP) in vivo (Sutherland et al., 2000). FAE animals were found to exhibit specific alterations in spatial learning. Mice showed significant deficits when tested in both a moving hidden platform task and a cue-placed competition task (Sutherland et al., 2000). FAE rats trained using a single-trial contextual fear conditioning (CFC) paradigm exhibited a significant deficit in associating the context with the shock, although they properly associate the cue (tone) with the foot shock (Weeber, Savage, Sutherland & Caldwell, 2001). These animals retained this deficit when tested from 24 to 72 hours after CFC training. FAE animals learned to associate the context with the shock when they were trained with three consecutive representations of the foot shock (Weeber et al., 2001). FAE animals trained using a single-trial (CFC paradigm were found to exhibit specific deficits in the release of ^{3}H-D-aspartate, a measure of glutamate release (unpublished data, as cited in Savage et al., 2001), and phospholipase C β1 activity in slices from both the hippocampus and medial frontal cortex (Weeber et al., 2001). In vitro studies in hippocampal slices revealed that glutamate release was also decreased in FAE animals on titanic stimulation but not under basal conditions (Savage et al., 1998).
<u>Mechanisms of Learning (Rats)</u> PKC-dependent phosphorylation of GAP-43 may be a critical step in synaptic plasticity mechanisms underlying learning (Savage et al., 2002).	The growth- and plasticity-associated protein GAP-43 is a substrate of protein kinase C (PKC). Phosphorylation of serine 41 in GAP-43 by PKC is known to change to functional properties of this protein (Savage et al., 2002). Perrone-Bizzozero et al. (1998) demonstrated that prenatal exposure to moderate levels of alcohol alters GAP-43 phosyphorylation in the hippocampus of adult offspring. Not only were the

Deficiency (Model)	Biological Mechanism
	PKC activity and the proportion of PKC-phosphorylated GAP-43 decreased in the hippocampus of these animals, but these levels did not increase in response to PKC activators. Tanner et al. (2004) concluded that "considering the role of PKC activation and GAP-43 phosphorylation in synaptic plasticity, our results suggested that deficient translocation PKC β_2 and PKCε in the hippocampus may mediate the electrophysiological and behavioural deficits observed in fetal alcohol exposed animals" (p. 113).
<u>Memory Impairments (Mice)</u> Memory impairments are linked to neurophysiological alterations that diminish activity-dependent enhancement of hippocampal synaptic neurotransmission in affected offspring (Savage et al., 2002; Sutherland et al., 1997). Prenatal ethanol exposure reduced hippocampal long-term potentiation in vitro (Swartzwelder et al., 1988) and in vivo (Sutherland et al., 1997). Enhancement of hippocampal glutamate release may play an important role in the acquisition of new spatial learning (Chang, et al., 2001; Gooney, Shaw, Kelly, O'Mara & Lynch, 2002).	Diminished activity-dependent potentiation of electrically evoked [3H]-D-aspartate (D-ASP) release. The mechanistic basis of fetal ethanol-induced synaptic plasticity deficits has focused on putatitive postsynaptic alterations in hippocampal NMDA receptor number, (Abdollah & Brien, 1995), NMDA receptor modulation (Costa et al., 2000), NMDA receptor-mediated functions (Weaver et al., 1993), $GABA_A$ receptor number (Bailey, Brien & Reynolds, 2001), and $GABA_A$ receptor modulation (Bailey, Brien & Reynolds, 1999). Neurochemical changes in ethanol-exposed offspring that could contribute to these activity-dependent synaptic plasticity deficits may include alterations in hippocampal glutamate receptors (Costa et al., 2000), postreceptor signal transduction systems (Weeber et al., 2001), and glutamate receptor-mediated functions (Weaver et al., 1993). Savage et al. (2002) reported reductions in hippocampal glutamate (Farr et al., 1988), NMDA, and kainite receptors (Farr et al., 1988b), and metabotropic glutamate receptor function (Queen et al., 1993) in prenatal ethanol-exposed offspring. Savage et al. (2002) suggested that the threshold for producing statistically significant reductions in these physiologic and behavioural measures of synaptic plasticity and learning is a maternal blood ethanol concentration (BEC) between 7 and 30 mg/dL. Prenatal ethanol exposure affects hippocampal glutamatergic neurotransmission in a way that

Deficiency (Model)	Biological Mechanism
	diminishes hippocampal plasticity and learning (Savage et al. 2002).
Deficits in learning, memory, and behavioural inhibition (Rats) Deficits in learning, memory, and behavioural inhibition similar to those seen following cholinergic functional disruption and neuronal damage within the septohippocampal system (Allen, Weeber, Savage & Caldwell, 1997)	PLC-β1 activities were significantly decreased by 20 to 30% in both the hippocampus and medial frontal cortex of FAE rats (Allan et al., 1997). Total CA^{2+}-dependent PLA_2 activity was 25% lower in the medial frontal cortex of FAE rats, but did not significantly differ from controls in the hippocampal formation. Cytosolic PLA_2 activities were significantly reduced in both the medial frontal cortex and hippocampal formation of FAE rats (Allan et al., 1997). These changes in CA^{2+}-dependent PLA_2 and PLC-β1 activities, coupled with reports of FAE-induced deficits in protein kinase C activity, indicate that prenatal exposure to moderate quantities of ethanol causes profound and long-lasting deficits in the cellular signaling mechanisms associated with activity-dependent synaptic plasticity and memory function (Allan et al., 1997).
Deficits in higher cognitive functioning (Rats)	Iterations in hormonal levels as a consequence of dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis may partially contribute to prefrontal cortex (PFC) abnormalities (Comeau, Winstanley, & Weinberg, 2011). Alterations in behaviour indicative of increased anxiousness in novel environments (Comeau et al., 2011). Prenatal alcohol exposure reprograms the HPA axis in utero, altering HPA tone throughout life. Subsequent modifications in the synthesis and release of hormones including corticotrophin-releasing hormone (CRH) and corticosterone produces an abnormal or heightened responsiveness to life-stressors that may further precipitate abnormalities in cognitive function (Comeau et al., 2011). The PFC continues to develop through puberty, corresponding with the maturation of cognitive processes. As postnatal development is largely influenced by experience, the developing PFC remains vulnerable to adverse pre-and postnatal environmental factors into adulthood (Comeau et

Deficiency (Model)	Biological Mechanism
	al., 2011).
Pathogenesis of depression (Human)	HPA axis dysfunction has been hypothesized to play a central role in the pathogenesis of depression, due to alterations in neurotransmitter systems. Hormones involved in the stress system have been found to modulate prefrontal dopamine neurotransmission, which may contribute to the impairments in prefrontal cortex function (Uban, Dodnar, Stepien & Comeau, 2011, p. 312). As well dopamine neurotransmission in the prefrontal cortex has a complex role in modulating functions mediated by this region, which include both executive function and mood systems (Uban et al., 2011)
Delay in maturation (Rats)	Prenatal alcohol exposure (PAE) alters reproductive or hypothalamic-pituitary-gonadal (HPG) axis function, which in turn affects reproductive function (Weinberg, 2010). In females, PAE delays the onset of puberty as well as reduces the reproductive window. Whereas in males, PAE reduces the perinatal surge of testosterone (Weinberg, 2010). Kisspeptins, products of the Kiss-1 gene may play a role in the regulation of reproductive hormone levels. PAE is believed to have a pre-adolescent reduction of Kiss-1 mRNA thus delaying the onset of puberty (Weinberg, 2010).
Heightened sensitivity to stress (Rodent models)	Partially due to reprogramming of the hypothalamic-pituitary-adrenal (HPA) axis in utero (Uban et al., 2011) This may alter their ability to mount appropriate responses. As well altering HPA axis (e.g., display impaired cognition), may be translated to the adoption of ineffective learning strategies in humans (Uban et al., 2011)
Reduction in antioxidant capacity (such as levels of Glutathione (GSH) and gluthathione peroxidase) (Human)	Reactive oxygen species (ROS) are small, highly reactive, oxygen-containing molecules that are generated in small amounts by the mitochrondria during the body's metabolic reactions and can react with and damage complex cellular molecules such as fats, proteins, or DNA (Mela & Obayan,

Deficiency (Model)	Biological Mechanism
	2007) Alcohol promotes generations of ROS (Wu & Cederbaum, 2003) which results in further free radical production and damage. The indirect mechanism involves interference with the body's normal defense against free radicals through numerous processes, particularly in the brain and liver; thereby reducing the levels of GSH and gluthanthione peroxidase (Cohen-Kerem & Korem, 2003).

A number of studies have demonstrated impairments in the social and adaptive behaviours of children prenatally exposed to alcohol. Research on adolescents and adults affected with FAS indicate obvious deficits in social skills and adaptive functioning (Streissguth et al., 1991). Whaley et al. (2001) discovered that the average 13- to 33-year-old with FAS displayed social skills at a 6-year-old level even when the individual had an "average range" IQ score.

In addition to educators, people in general tend to misinterpret normal responses in individuals with FAS or FAE (Table 2.2). As well, biological deficiencies have to be understood in order to make feasible policy implications including support services to manage individuals with FASD. Doctor (2000) refers to this management, supporting a mother and child with FAS, by creating an "external brain." This external brain provides more guidance and direction than individuals with FASD can provide for themselves (Doctor, 2000). However, as individuals affected by FASD age, the concept remains constant but the services provided need to become more age- and behaviour-specific (Doctor, 2000).

Table 2.2 Common Misinterpretations of Normal Responses in Individuals with FAS and FAE.

Behaviour	Accurate Interpretation	Biological Deficit
Noncompliance	Has difficulty translating verbal directions into action Doesn't understand	Less proficient at information processing (Jacobson et al., 1994) Deficits in language skills, word comprehension, articulation, and naming ability (Abel, 1990; Becker et al., 1990; Conroy,

Behaviour	Accurate Interpretation	Biological Deficit
		1990; Mattson et al., 1997)
Repeats the same mistake	Can't link cause to effect Can't see similarities Has difficulty generalizing	"Slow learners" becomes "spacey" during tasks Makes frequent omission errors (Streissguth et al., 1986)
Doesn't sit still	Has neurologically based need to move while learning Is experiencing sensory overload	Deficits in motor functioning Short attention span (Chandler et al., 1996; Roebuck et al., 1999)
Doesn't work independently	Has chronic memory problems Can't translate verbal directions into action	Deficits in visual, spatial and auditory memory (Kodituwakku, 2009; Mattson et al., 1996; Rasmussen, 2005; Streissguth et al., 1994) Lower executive functioning (Kodituwakku et al., 1995; Kodituwakku, 2009; Rasmussen, 2005)
Doesn't complete homework	Has memory deficits Is unable to transfer what is learned in class to the homework assignment	Intellectual deficits including articulation, naming, language skills, and number processing (Abel, 1990; Becker et al., 1990; Conroy, 1990; Mattson et al., 1997) Low arithmetic, reading, and spelling skills (Coles et al., 1991, Jacobson et al., 1993) Lower IQ (Jones et al., 1973; Mattson et al., 1997; Streissguth et al., 1991)
Is often late	Doesn't understand the abstract concept of time Needs help organizing	Slower reaction time on vigilance tasks (Streissguth et al., 1986) Lower executive functioning (Kodituwakku et al., 1995)
Uses poor social judgment	Is not able to interpret social cues	Deficits in expressive and receptive language skills

Behaviour	Accurate Interpretation	Biological Deficit
	from peers Needs help organizing	(Jansen et al., 1995) Lower executive functioning (Kodituwakku et al., 1995)
Is overly physical	Is hyper-hypo sensitive to touch Doesn't understand social cues regarding boundaries	Deficits in expressive and receptive language skills (Jansen et al., 1995) Lower executive functioning (Kodituwakku et al., 1995)
Steals	Doesn't understand concept of ownership over time and space Demonstrates immature thinking (finders keepers)	Less proficient at information processing (Jacobson et al., 1993) Lower executive functioning (Kodituwakku et al., 1995)
Lies	Has problems with memory and/or sequencing Is unable to accurately recall events Tries to please by telling you what they think you want to hear	Deficits in visual, spatial and auditory memory (Mattson et al., 1996; Streissguth et al., 1994) Lower executive functioning (Kodituwakku et al., 1995)

We are beginning to understand the complexity of health and social factors that influence an individual affected by FASD. This intricacy of conditions further complicates the management of associated health problems. These individuals typically face problems of privacy and autonomy, are stigmatized due to labelling, and have barriers to access and treatment (Down, 2010). As well, the "invisibility of FASD" may complicate the daily living of these individuals. Without an FASD diagnosis, many of the FASD effects can be misinterpreted as "independent problems reflective of a challenging or disruptive personality type or persistent behavioural problems" (Rutman, La Berge, & Wheway, 2005, p. 2).

Criteria and Diagnosis for FASD

The diagnosis of FAS, which has remained relatively unchanged since the mid-1970s, is based on a triad of features: (1) pre- and postnatal growth deficiency, (2) a pattern of craniofacial malformations, and (3) central nervous system (CNS) dysfunction. The first pronounced feature is growth retardation which can include prenatal growth deficiency (e.g., decreased birth weight for gestational age) or postnatal growth deficiency (lack of catch-up growth even when there is adequate nutrition and a low weight to height ratio) (Bertrand et al., 2004; O'Leary, 2004).

The second feature of FAS, craniofacial malformations, can include short palpebral fissures, maxillary hypoplasia, epicanthal folds, thin upper lip, and flattened philtrum, which is an absent or elongated groove between the upper lip and nose (Bertrand et al., 2004; O'Leary, 2004).

Finally, the third feature of the FAS triad is central nervous system (CNS) anomalies or dysfunction which includes microcephaly or other structural brain abnormalities where no significant catch-up is evident through early childhood, causing a developmental delay. Other complexities associated with the central nervous system include social and motor performance related to mental age (not chronological), intellectual disability, and neonatal problems such as irritability and feeding difficulties (Bertrand et al., 2004; O'Leary, 2004). In 1996, the Institute of Medicine's diagnostic criteria for partial FAS/FAE was expanded, identifying it as a complex pattern of behavioural or cognitive dysfunction that could not be explained by developmental maturity or family home environment and that consists of the following (O'Leary, 2004, p. 3):

- Difficulties in learning
- Poor school performance
- Poor impulse control
- Problems in relating to others
- Deficits in language (understanding and speaking)
- Poor ability for abstract thinking
- Poor arithmetic skills
- Problems in memory, attention, or judgement.

FASD Diagnostic Issues

Currently, there is no objective laboratory test for diagnosing FAS and a finding relies on reports of alcohol use by the mother during pregnancy and/or around the time of conception (Bertrand et al., 2004; O'Leary, 2004). As Simpson et al. (1997) point out, clinical criteria for any birth defect syndrome, such as FASD, are based on a characteristic pattern of major and minor anomalies that are unique to the disorder. Because of the natural variation in human biology, no list of this kind can be fully specific or particularly reliable; it will include characteristics from the rare individual with an alternate condition and exclude those of some individuals with incomplete expressions of the specific condition (Sampson et al., 1997). Therefore, these inconsistencies can be identified theoretically, if a specific biologic marker or pathophysiologic test is linked to the cause of the diagnosis; however, currently there is no specific test for the birth defects caused by ethanol (Sampson et al., 1997).

As well, a diagnosis of FAS can be unreliable and biased because few clinicians are trained to recognize it. There is a lack of validated checklists or laboratory tests by which inexperienced examiners may gain experience and calibrate his or her judgments based on published characterizations (Clarren & Smith, 1978; Sokol & Clarren, 1989). Although the ratings of facial features of FAS by medical providers and biomedical scientists appear to be significantly correlated, findings suggest a low sensitivity and specificity for FAS (Abel et al., 1993).

In addition, clinicians are aware of the stigma attached to FAS which leads to a decreased likelihood of a FAS diagnosis in the official medical record, especially for families of higher income or social class (Abel et al., 1993). Another difficulty arises when FASD anomalies are noted singularly over time rather than when they are seen together as parts of a whole diagnosis (Little et al., 1990).

Astley and Clarren (1995) suggest that objective measures of FAS facial features can be combined in a scoring system to prevent the discrimination of the ratings derived from a trained dysmorphologist. However, this scoring system is intended mainly as a screening tool and not as an objective clinical test (Astley & Clarren, 1995). Researchers have been working on a computer program for identifying cases of FAS based on a

clinician's rating of facial, congenital, and neurobehavioural anomalies, but there is still no published validation of this procedure (Astley & Clarren, 1995).

Unreliability and Inconsistencies

There are numerous limitations with the diagnosis criteria. Facial features as well as growth retardation often change with age and between ethnic populations, making diagnosis difficult (Streissguth et al., 1994). Generally, diagnosis is made on infants and young children even though central nervous system dysfunction and facial morphology may be difficult to assess prior to 2 years of age (Rosett, 1980).

In longitudinal studies, Streissguth et al. (1994) discovered that by adolescence, the FAS facial morphology becomes less distinctive and the individual's weight approaches the mean. However, a number of FAS signs persist, including microcephaly, short palpebral fissures, indistinct philtrum, a thin upper lip, and mild micrognathia (Sporh et al., 1994). In addition, the central nervous system abnormalities remain throughout the life span, as do numerous psychiatric disorders that have been identified as occurring in FAS adolescents (Sporh et al., 1994; Streissguth, et al., 1994).

The diagnosis of FAS or partial FAS, recently referred to as ARND, requires the presence of a history of prenatal alcohol exposure. There is, however, no widespread agreement on the dose, the timing, or the duration of exposure necessary to cause FAS or partial FAS/ARND (Day et al., 1993). Research indicates that the outcome of exposure has been difficult to assess, partially due to many challenges: Measuring the exposure parameters of alcohol dose and consumption timing, genetic factors influencing susceptibility, protective factors, and lack of agreement on diagnostic criteria (Burd et al., 2003).

Finally, with the use of the term *FASD* and the expansion of the various categories within the spectrum, new complexities have been created regarding diagnosis. The diagnosis of FAE, ARBD, and ARND and the estimation of their incidence are more difficult than that of FAS, which in itself has been problematic. The relative specificity of the FAS diagnosis makes it practical as well as scientific (Goodlett & West, 1992). However, ARBD and ARND are not actually syndromes, but the

appearance of FAS characteristics individually associated with, but not exclusive to, prenatal alcohol exposure. ARBD and ARND can be “lower dose” manifestations of FAS, but they may also reflect a number of factors including the timing of exposure, dose of teratogen, genetic factors in mother or fetus affecting metabolism or susceptibility, and interactions with other environmental exposures (Chernoff, 1980; Goodlett & West, 1992; Hanson, 1990).

Development of Objective Measures

There has been a major push for more consistency in the diagnosis of FASD, particularly in clinics throughout the Canadian Northwest. The current guidelines have acknowledged and addressed some discrepancies. Original facial recognition characteristics for FASD did not consider ethnic differences; therefore, improved criteria and norms are based on thousands of measurements (of palperbral fissure lengths) for individuals of all ethnicities between the ages of 6 to 16 (O’Malley, 2009). Diagnosis is not based on a set number of tests or specific tests required to determine the cognition and performance of the suspected individual (Clarren, 2009). Some standardization would allow comparisons among individuals. In Canada, the 4-digit code needs to be further refined to detect the severity of brain anomalies on a scale of “neurodevelopmental injury” in order to identify those individuals with non-visible FASD characteristics so they can obtain much-needed support services (Clarren, 2009). Lastly, a new system that considers co-morbid etiological conditions has been proposed by professionals in the field (Clarren, 2009). Furthermore, research in this area has been expanding exponentially, and new techniques and diagnostic criteria are being evaluated (Table 2.3; see Astley, 2013).

Table 2.3. Current and Experimental Diagnostic Measures Used to Identify Individuals with FASD.

Diagnostic Measures	Descriptions of Test Attributes Examined	Source
Maternal Biomarkers	Blood tests such as gamma glutamyl transerase (GGT), mean corpuscular volume (MCV), carbohydrate-deficient transferring (CDT) and maternal hair indicate maternal alcohol consumption.	Stratton, Howe & Battaglia, 1996
Biomarkers	Growing scientific understanding of the teratogenic effects of alcohol-with emergence of biomarkers (eg. Fragile X and Retts).	Down, 2010 Coles, 2011a, p. 342

Diagnostic Measures	Descriptions of Test Attributes Examined	Source
	Epigenetic biomarkers of prenatal alcohol exposure-changes in DNA methylation as a function of prenatal alcohol exposure.	
Epigenetics	Epigenetic mechanisms are involved in the regulation of cellular growth and differentiation, and are therefore plausible targets for aetiological research.	Haycock, 2011, p. 355
Ultrasound	Allows for evaluation of fetal anatomy and detection of abnormalities including heart defects, central nervous system abnormalities, cleft lip and palate.	Hull, 2009
Infant meconium samples	Meconium is analyzed for fatty acid ethyl esters (FAEEs), a biologically stable metabolite of ethanol, a gas chromatography-flame ionization detection to objectively quantify the prevalence of prenatal alcohol exposure. Meconium is also analyzed for drugs of abuse using enzyme-linked immunosorbent assays. Haemoglobin acetaldehyde adduct (HbAA) meconium is also used as a biomarker for FASD.	Hutson, 2007, p. 330; O'Malley, 2009; Loock, Conroy & Koren, 2013
Fetal frontal cortex development	Fetuses exposed to heavy alcohol tend to have a fetal frontal cortex length below the 25th percentile	Waas, Persutte & Hobbins, 2001
Fetal breathing movements	Suppression of fetal breathing movements have been detected after 15 min of maternal alcohol drinking.	McLeod, Brien, Loomis, Carmichael, Probert, & Patrick, 1983
Families First Screening Form	Brief measure of biological, social and demographic risk factors used to track these factors for planning services and policy development and to direct families to appropriate resources such as parenting programs, addictions treatment, child development clinics, and financial assistance.	Isbister, 2009, p. 154
Magnetic Resonance Imaging (MRI)	Imaging technique that employs a powerful magnetic field to align the magnetization of some atoms in the body, then uses radio frequency fields to systematically alter the alignment of this magnetization. The power of the magnet in an MRI system is rated using a measure known as a Tesla. For human clinical imaging, magnetic strengths in the range of 0.5 to 3.0 Telsa are used. Much more powerful magnets are used for basic research, providing excellent resolving power. MRI illustrates loss of portions of the corpus callosum in the brains of individuals with FAS. 3-D reconstructions made from MRI scans provide	Sulik, 2011

Diagnostic Measures	Descriptions of Test Attributes Examined	Source
	information regarding shape and volume.	
Diffusion tensor imaging (DTI)	DTI is an MRI modality that is based on the diffusion of water in biological tissues. The rate and direction of water diffusion can be quantified. If diffusion is uninhibited/random it is referred to as isotropic. If it is restricted/nonrandom it is anisotropic. DTI was used to examine white matter abnormalities over a wider age range (5-30 years) and to test if brain abnormalities are correlated with cognitive functioning. Differences in diffusivity within the brain allow identification of fiber orientation and microstructure. A quantitative MRI method that can identify white matter tracts and yield parameters, such as mean diffusivity (MD) and fractional anisotropy(FA), which reflect structural integrity of white matter.	Sulik, 2011; Treit, 2011
fMRI	Functional assessment in the scanner - whole brain scan for activity levels while child is participating in a N-back working memory task.	Astley, 2007; 2009
Palpebral fissure lengths (FPL)	Used for diagnoses - dysmorphological assessment has significant importance in identifying individuals with craniofacial features related to prenatal alcohol exposure; however, it remains problematic among clinicians to measure accurately.	Cranston & Chudley, 2007, p. 318
3-D photography	Neuroimaging techniques used to operationalize the characteristics of the facial features.	Coles, 2011a, p. 342
MEG	Magneto-encephalography (MEG) is a non-invasive neuroimaging methodology which detects ongoing brain activity with exquisite temporal resolution. To characterize brain network dynamics in adolescents with FASD and normal controls utilizing MEG. While severely affected children display a characteristic pattern of physical dysmorphia, the majority of alcohol-exposed children may not, even though they may experience comparable levels of cognitive and behavioural deficits. The study objective is to identify neuromagnetic markers of prenatal alcohol exposure which may be useful for the characterization of specific deficits and for planning of targeted interventions for individuals with FASD. MEG presents the opportunity to extend these studies through the imaging of neuronal dynamics in multiple cortical areas as well as subcortical regions such as hippocampus, amygdale and cerebellum. Predictive capability and plasticity are characteristic features of cortico-cerebellar networks. Moreover, cerebellum has	Tesche, 2011, p. 181; Ito, 2008

Diagnostic Measures	Descriptions of Test Attributes Examined	Source
	been suggested to play an important role in adaptive control of behaviour through the development of models for mental representations that are critical to affect cognitive and affective processes.	
Event-related Brain Potential (EBP)	Two ERP components have been identified that reflect performance monitoring via internal and external feedback mechanisms. ERPs are small voltage fluctuations recorded through electrodes placed on the scalp which provide information about the connections between neurons. This electrical activity provides information about what parts of the brain are involved in the particular mental operation and characteristics patterns of electrical activity for various abilities.	Baker & Gruppuso, 2009
Electorncephalographic studies (EEE)	EEE studies have already revealed differences in brain dynamics between adolescents with FASD and normal children. Differences have been observed both in evoked-response P300 amplitudes and latencies in an oddball paradigm and in the rhythmic component of the resting EEG.	Kaneko, Philips, Riley & Ehlers, 1996
Adult interview	Learning/memory/information processing, behavioural/emotional regulation, sensory, motor, social skills, daily living skills, communication, safety, planning/temporal skills, abstract thinking, judgement and working/jobs.	Horne, Gerry, Byrne, Gerry & Down, 2010
NEPSY - Developmental Neuropsychological Assessment	Composite total scores for test domains (attention/executive functions, language, sensorimotor functions, visuospatial processing, memory and learning). Patterns of subtest and qualitative scores on the NEPSY are significantly predictive of an FASD diagnosis - such predictors will be helpful in diagnosis, especially for programs where fully psychometric assessments are more difficult to obtain.	Scott, Huber & Gravel, 2013; Longstaffe & Hanlon-Dearman, 2009; Hanlon-Dearman & Penner, 2007
Language test performance	Neuropsychological Performance Executive functioning: Tower of California test.	Riley, 2007, pp. 147-148
PPVT-III	PPVT- (Peabody Picture Vocabulary Test) III is a recognition test of single word receptive vocabulary and can be compared to EVT scores to differentiate individuals with alcohol related diagnoses.	Woodworth, Conroy & Lane, 2007
Expressive Vocabulary Test (EVT)	EVT is an expressive vocabulary test because the retrieval and synonym task requires higher level thinking than the recognition test of the PPVT-III, it is possible that the score differences help quantify this frequently made qualitative description of one of the effects of prenatal exposure to alcohol.	Woodworth et al., 2007

Diagnostic Measures	Descriptions of Test Attributes Examined	Source
Fine motor skills	Using grooved pegboard test	Riley, 2007
BRIEF	Behaviour Rating Inventory of Executive Function. Parental and teacher rating scale of a child's executive functioning behaviours in everyday situations and settings, measured across eight scales (inhibit, shift, emotional control, initiate, working memory, plan/organization of material, and monitor).	Rasmussen, 2007, p. 314
Speech language pathology assessment	Speech language pathology assessment of the communication and social communication brain domains in FASD. Preschool Language Scale-IV, the Clinical Evaluation of Language Fundamentals Preschool-2, and the Clinical Evaluation of Language Fundamentals-2.	Proven, 2009, p. 377
Hearing impairments	Sensorineural hearing loss has been described in elevated rates in children with craniofacial anomalies as a result of prenatal exposure, related to toxic effects on the auditory nerve. Auditory processing deficits have also been described in association with prolonged ABR latencies. Elevated rates of conductive loss in children with FAS and recurrent otitis media with effusion has also been described with rates over 80% -- with suggestion that this may be related to craniofacial dysmorphism and associated Eustachian tube dysfunction.	Hanlon-Dearman & Proven, 2009, p. 385
Oculomotor control	Children with FASD have increased saccadic reaction times, increased intra-subject variability in performance of eye movement tasks and increased direction errors (saccades made in the incorrect direction relative to instruction), in comparison to age- and sex-matched control children. Eye movement recording can be used as an objective measure of brain dysfunction in FASD, revealing behavioural deficits independent of facial dysmorphology. Eye movement tasks can now be coupled with functional magnetic resonance imaging to identify brain structures that contribute to these behavioural deficits.	Reynolds, 2009, p. 172; Paolozza, 2013
Interrogative suggestibility in children with FASD	Understanding secondary disabilities - behaviours and potential vulnerability assessed interrogative suggestibility in children with FASD using the Gudjonsson's suggestibility scales - the scales provide measures of 'Yield' (i.e., the extent to which individuals respond affirmatively to leading questions) and 'Shift' (i.e., the extent to which individuals alter responses when provided with critical and negative feedback). Participants listened to a short recorded story about a robbery or a non-criminal event and were told that they would be asked to recall (i.e., immediate free recall) the story at the end of the recording. The delayed free recall test was completed following a filler task and before	Gruppuso, 2009, p. 375

Diagnostic Measures	Descriptions of Test Attributes Examined	Source
	administering leading and non-leading questions. After answering the questions, participants were given negative feedback indicating that their responses contained errors and that the questions would be readminstered. Initial analysis of responses indicates that yield and shift scores are high among a small group of children with FASD.	

With the advance of technology, diagnosis of FASD may become more standardized and economical. High-resolution magnetic resonance imaging (MRI) has provided visual documentation of a localized specific pattern of cerebellar vermal dysmorphology in alcohol-exposed individuals (O'Hare et al., 2005). In addition, researchers are combining methods to validate their hypotheses. O'Hare et al. (2005) have negatively correlated verbal learning and memory performance to anterior vermal dysmorphology. Hopefully, this technology and new application can indicate dysmorphology early. This example stresses the fact that an understanding of the damage can aid in the evaluation for future medical and educational supports.

Some debate exists about the efficacy of applying FASD to an international classification system. For example, the goal of the International Classification of Functioning (ICF), developed by the World Health Organization, is to provide a better foundation for the study and understanding of health conditions and to establish a common language to improve communications surrounding health-related determinants (Andrew, 2011). Although this approach may give "a more complete picture of FASD in all communities" by identifying barriers and suggesting required resources, it may be just another framework that reiterates the same FASD discourse, but doesn't add anything to final outcomes for those individuals affected by FASD (Andrew 2011, p. 216).

Similarly, and building upon the ideals of the ICF, the Internal Coalition Outcome Heirarchy (ICOH) provides a comprehensive framework for evaluating the internal organization of a coalition. This model uses seven theoretical constructs[12] to evaluate

[12] The seven theoretical constructs include shared social vision, efficient practices, knowledge and training, relationships, participation, activities, and resources (Cramer, Atwood, & Stoner, 2006).

the process, outcome, and impact functions of a coalition (Clarke-McMillen, 2010, p. 241). The ICOH has been proposed to and implemented by the Kingston FASD Action Network (Clarke-McMillen, 2010).

Another suggestion to aid in the identification of prenatal alcohol exposure is the standardization of Canadian Prenatal Record Forms (Premji & Semenic, 2009). The existing forms do not contain the required background information and contextual factors needed to identify individuals at high risk for FASD. Therefore, major changes would need to be implemented in order for these forms to be of any benefit (Premji & Semenic, 2009). In addition, as the diagnosis of FASD requires the confirmation of the mother's alcohol use while pregnant, efforts have been employed to obtain more accurate FASD data collection and reporting such as the Canadian Perinatal Surveillance System (Badry & Bradshaw, 2010).

The hope is that these new diagnostic measures and standardization will reduce the misclassification of FASD characteristics that currently exist. In addition, resources need to be provided to better equip doctors with the knowledge they need to detect the possibility that an individual has been affected by prenatal alcohol exposure and with the willingness to refer the individual to diagnostic specialists. More resources also need to be provided to accredited diagnostic specialists so they have the equipment necessary to make proper assessments, thereby making diagnosis more accessible. Accessibility is of particular concern in B.C., where there are five different health regions, each with its own unique composition including urban, rural, remote, and Aboriginal areas. To further complicate resource allocation, each region has its own varying population with specific needs and subsequent required funding.

Is FASD a Social Policy Issue?

The detrimental effects resulting from prenatal ethanol exposure continues to be the most common preventable cause of mental disability (Abel & Sokol, 1986). Although the role of the mother is not completely understood, research into FASD has resulted in a better understanding of the many levels of FASD, of the major malformations and disabilities characteristic of it, and of better diagnostic tools. However, the cycle of alcohol abuse and FASD continues, largely unabated. It has been estimated that the

lifetime cost of a person affected by FASD in Canada is $2.8 million (Thanh & Jonsson, 2009). In addition to the financial and emotional costs associated with it, FASD is linked to increased criminal activity and victimization (Fast, Conroy, & Loock, 1999). From a policy perspective, therefore, it is critical that this cycle be prevented from causing so much damage individually and systemically. Comprehensive strategic plans are needed from all levels of government for directing policy, prevention, intervention, treatment, and research.

Social policy is often criticized for its thin evidentiary basis (Fischer, 2003; Mears, 2007). Likewise, in recent years, one of the main criticisms of public health policy has been its lack of a robust evidentiary basis (Bowen et al., 2005). Some policy critics have suggested that policy would benefit from "the frequent application of gold-standard approaches to complex interventions and through adopting a more integrated approach to evaluation and implementation" (Judge, Platt, Costongs, & Jurczak, 2006, p. 3). FASD overlaps both criminological and public health policy development. Policies for addressing the needs of high risk women as well as individuals affected by FASD could clearly benefit from an integrated, multilayered, evidence-driven approach (Huitson, 2009).

Research has indicated that a comprehensive prevention program for FASD and all of its subcategories FAS, pFAS, FAE, ARND, and ARBD would require numerous approaches and varying knowledge from numerous disciplines (Chudley et al. 2005). May (1995) believes that etiology and solutions should include culture, society, behaviour, and medicine. In order to capture all of May's factors, it is necessary to adopt an integrated systems perspective, which is based on the belief that behaviour is the result of continuous interactions between people and the environment.

Public systems such as health, education, and the criminal justice system do not adequately manage the individual affected by FASD. Consequently, current FASD policies, which impact many of these systems, will be evaluated in this dissertation using a comprehensive, integrated, multileveled paradigm.

Brantingham and Faust (1976) designed a conceptual model of crime prevention (Table 2.4) which was derived from the Public Health Paradigm consisting of three levels of prevention: primary, secondary, and tertiary. In the crime prevention model, the aim

of primary prevention is to reduce crime by "addressing underlying factors that have a basic influence on everyone shaping people, sites, and situations that are amenable to criminal events" (Brantingham, Brantingham, & Taylor, 2005, p. 274). These factors can include sociological, physical, psychological, and economic influences (p. 274). The objective of secondary prevention is preventing high risk "individuals, groups, social conditions, or physical settings" from becoming involved in criminal events (p. 274). Prevention approaches could include specific education programs for groups at risk, such as children with parents who have a criminal or abusive history. The goal of tertiary prevention is preventing the reoccurrence of a criminal event. Tertiary prevention might include physical modifications in frequently victimized locations, rehabilitation programs, support services, and deterrence programs (Brantingham, et al., 2005).

Table 2.4. Criminological Paradigm, A Conceptual Model of Crime Prevention (Brantingham & Faust, 1976, p. 289).

Primary	Secondary	Tertiary
Environmental Design	Early identification	Reform Community treatment Institutional treatment Punishment
General social and physical well-being programs	Pre-delinquent screening	Rehabilitation Training Support Surveillance
Crime prevention education	Individual intervention Neighborhood programs	Incapacitation Institutional custody

Originally, the distinction between the three levels of prevention was made in the field of preventative medicine. The goal of primary prevention was to lower rates of new cases by instigating some actions focused at the public to counter the perceived risky conditions before the onset of the illness (van Dijk & de Waard, 1991). Secondary prevention entailed measures intended for individuals or groups identified as experiencing early symptoms of the illness, and tertiary prevention was aimed at those having a disease (van Dijk & de Waard, 1991).

In the medical field, the goal of prevention is to stop or alleviate "major human dysfunctions", as well as to eradicate or diminish the origins of the disorder (Coie et al., 1993, p. 1013). Therefore prevention measures are directed towards the methodical

study of risk and protective factors, those being the "potential precursors of dysfunction or health" (Coie et al., 1993, p. 1013). It has been recognized that etiological models need to clearly address the complex genetic, biomedical, and social processes "believed to influence the incidence and prevalence" of the phenomenon of interest (Coie et al., 1993, p. 1013). These have only been recently applied to the field of Criminology and Social Sciences.

This integrated policy paradigm has the same three levels of prevention: primary, secondary, and tertiary (Table 2.5). The primary level prevention is similar to Brantingham and Faust's (1976), addressing "conditions of the physical and social environment that provide opportunities for or precipitate" the creation of an individual affected by FASD (p. 290). At this level, the goal of the intervention is to modify those environmental conditions that increase the possibility of maternal drinking. For example, many women with children affected by FASD live in a social and cultural milieu that tolerates, ignores, or is unsuccessful in dealing with problem drinking (May, Hymbaugh, Aase, & Samet, 1983).

Table 2.5. Tri-level Policy Paradigm for FASD.

Primary	Secondary	Tertiary
Modification of environment that increases the possibility of material drinking	Early identification and diagnosis of high risk mothers for FASD	FASD affected individuals – early identification, diagnosis, and management
Education and health promotion	Intervening "strategies" targeted at high risk women	Educational programs
Available services and support	Available services and support	Community treatment
Urban/Rural Community	Training	Available support
Research	Research	Research Criminal Justice System

The secondary level prevention characterizes the early diagnosis of and intervention with high risk women or mothers. Research estimates that from 13.2% to over 50% of pregnant women drink alcohol (Leonardson & Loudenburg, 2003). This high percentage of drinkers should be the focus of intervention, specifically initiatives should provide and support a healthier lifestyle for these women. Although extensive literature exists on the risk and protective factors for FASD, current policies and practices have not been sufficiently evaluated utilizing this information or available data sources.

The tertiary level prevention targets those individuals affected with FASD. This level encompasses intervention throughout their lives, so they will "not commit crimes" and can function in the community. Without appropriate support and services, individuals affected by FASD are more likely to develop secondary disabilities, which are not innate but evolve as a consequence of primary disabilities as the person matures (Morley, 2006). These secondary disabilities experienced by affected individuals can include "mental health problems, disruptive school experience, trouble with the law, confinement for mental health, drug and alcohol problems, or criminal issues, inappropriate sexual behavior, problems with employment, [in]dependent living, and problems with parenting" (Morley, 2006, p. 13). For instance, an "undiagnosed" FASD child may perform poorly in school as a result of learning difficulties. These secondary disabilities can result in "marginalization during formative years, disruptive school experiences, as well as lifelong struggles related to low educational achievement" (p. 13). The broad number of issues that may be present in an FASD person's life clearly demonstrates the need for an integrated approach of various health and education services and supports throughout the individual's lifetime.

In addition, research has indicated that the greatest risk factors associated with secondary disabilities in FAS/FAE are (a) having an IQ over 70 (lower IQ's are likely to get more services and interventions) and (b) exposure to sexual or physical violence, which occurs at a rate of 72% for individuals with FASD (Kellerman, 2002). As well, those individuals affected with FASD who also had previous exposure to violence are four times more likely to exhibit inappropriate sexual behaviour, which is one of the secondary disabilities (Kellerman, 2002).

The tri-level model I use as the organizational framework for this dissertation is not the only model that exists; however, I also incorporate an integrated systems theory model within each level, hence the uniqueness of this research. Crawford (1998) concurs with the three levels of prevention, although he differentiates between social and situational approaches within each level. Van Dijk and de Waard (1991) use a two-dimensional typology of crime prevention, where the first dimension consists of three prevention levels, while the second involves routine-activity theory, which includes a victim-oriented, situation-oriented, and offender-oriented focus (Van Dijk & de Waard, 1991). Furthermore by utilizing Robinson's integrated systems approach (cell, organ,

organism, group, community/organization, and society) within each of the levels of prevention, all of these alternate frameworks are incorporated into the one model.

Studies on maternal alcohol, tobacco, and illicit drug (MATID) use and child developmental outcomes employ the behavioural teratology model (Lester, 1999). This research isolates the drug's effects, thereby controlling other variables, and explains the child's outcomes due to "multiple antecedent variables" (Lester, Andreozzi & Appiah, 2004, p. I,5). However, this approach does not consider drug exposure as part of the developmental model. Generally, environmental variables such as drugs are treated as confounding factors rather than as the primary focus (Lester et al., 2004).

Policy approaches for MATID use include primary, secondary, and tertiary prevention strategies, similar to the categories in this policy paradigm. The complexity of maternal drug use during pregnancy has been recognized and identified in the research as including "substance abuse, psychological, parenting, social, family and medical issues", all of which are considered in prevention strategies (Lester et al., 2004, p. I,5). Though the knowledge base seems to be comprehensive, our policy approaches do not seem to address the complexities inherent in the problem. Lester et al. (2004) believe it is time for a national consensus on how to deal with maternal prenatal drug use that reflects our current knowledge in research and treatment, and expresses a fair and unbiased attitude towards these women and their children (Lester et al., 2004).

The aim of the comprehensiveness of the tri-level model proposed in this dissertation is to address the five notable problems with existing crime policy and policy in general (Mears, 2007). Mears identifies the following challenges:

> 1) a lack of empirical assessment of the need for them [policy], 2) a range of design issues, including gaps between crime theory and policy, and, most notably, the pursuit of silver bullet solution, 3) a range of implementation issues, including disjunctures between ideal and actual practice, 4) the lack of rigorous impact evaluations and the sometimes misplaced emphasis on them, and 5) a scarcity of cost-efficiency analyses for guiding investment decisions. (p. 667)

Besides these considerations, research suggests that comprehensive policies that are directed at multiple causes of crime are more prone to decrease crime than those initiatives that focus on fewer causes (Mears, 2007).

The policy paradigm utilizes an interdisciplinary perspective and a systems theory approach, which involves the integration of contributions from all disciplines, as well as an understanding of the relationship of related parts (or system components) to the "whole" system with regard to the phenomena of interest (Stewart & Ayres, 2001). With a systems approach, the linkages, which may be hierarchical or network-based, between components that may affect variables are understandable and are relevant to policy (Stewart & Ayres, 2001). Steward and Ayres (2001) believe that the systems theory "enables analysts to get a handle on the complexity" and that "policy responses cannot therefore be 'designed' but represented a way of navigating through the problem" (p. 83). When one understands the component parts, linkages, and contributions from all disciplines, a more complete picture of the "problem" is achieved and more appropriate policies can be developed.

For example, the integrated systems perspective suggests that "individuals experience variations in protective factors (things that decrease the likelihood of behaving in an antisocial way) and risk factors (things that increase the likelihood of behaving in an antisocial way)" (Robinson, 2004, p. 46). In other words, individuals are not the same in terms of the advantages and disadvantages they encounter or are born with (Robinson, 2004). Therefore, a behaviour is based on the presence of and balance between protective and risk factors.

Current policy approaches to FASD have had limited success and have created many challenges partly due to their narrow focus such as the child-centred focus, the Aboriginal women focus, or the simplistic focus on alcohol and blaming discourse (Poole, 2007a). It has been recognized that substance abuse of high risk women is influenced by a number of factors; therefore, addressing these determinants to improve women's health, in general, may succeed where other approaches have failed (Astley, Bailey, Talbot, & Clarren, 2000; May, 1995). Poole (2007a) proposed a women-centred policy framework for the prevention of FASD which utilized the primary/ secondary/tertiary model. Here the goal was to "prevent FASD and improve the health of women of childbearing years" (p. 297). The three levels of prevention included:

> efforts on the community level to address multiple determinants of health, brief interventions with all women of childbearing years to inform and assist them, co-ordinate networks of perinatal services to research at-risk women and their families. (p. 297)

However, as the model name states, all three levels focus on the mother and the prevention of FASD, with the ideal outcome being the elimination of FASD. The model, therefore, does not address those individuals already affected by FASD.

In addition, Greaves et al. (2002) proposed a mother-centred policy framework for those mothers and other women who use substances. The mother-centred focus is an attempt at more positive social policies and programming that encourages treatments as well as provides services that minimize health risks to these women. This framework consists of three essentials:

> mother-centred policy values, which articulate the bases for developing policy to support the mother-child unit, a policy filter, which is a tool for testing policy, and strategies for action and inclusion, which focus on processes for developing policy in a mother-centred manner. (p. 441)

The Canada Northwest Fetal Alcohol Spectrum Disorder (FASD) Research Network has recognized the myriad interrelated issues that contribute to the "FASD problem". They have focused prevention strategies and support services on addressing these issues as well as barriers that affect women's and children's health (NATFASD, 2010). Prevention efforts involve a logical framework that includes (1) individual information relevant for change, (2) direct dealings with high risk women, (3) FASD prevention programs placed within a health context, and (4) FASD prevention concepts integrated into other initiatives for high risk women (Clarren & Salmon, 2010, p. 23).

The government of Alberta embraces the same preventative health care model (primary, secondary, and tertiary) to organize their discussion on lifestyle behaviours. The government recognizes that an understanding of "the nature of the lifestyles and people's health belief models" is required to achieve and sustain healthy lifestyle changes throughout the lifespan (Basford, et al., 2004, p. 28). As well, the solution to prevention is "leadership provided through meaningful policy emanating from government departments (e.g. vehicle, social, and health departments)" (p. 37).

Similarly, May (1995) describes in great detail a “multiple-level, comprehensive program with primary, secondary, and tertiary prevention components” (p. 1550). Although the model is comparable to the complete and comphrehensive model I propose, prevention strategies are categorized into short- and long-term. Primary prevention focuses on reducing the predisposition of a problem, whereas, secondary prevention concentrates on decreasing the extent of an existing problem, and tertiary prevention minimizes complications once the problem is established (May, 1995). It appears that secondary and tertiary prevention show more potential for short-term reduction of FAS and ARBD prevalence, however, integrated strategies produce short- as well as long-term effects (May, 1995).

May (1995) believes that each prevention level must have a corresponding “aggregate level of maternal drinking” and other risk factors successfully “influence the risk, causes, and actual outcome of FAS and ARBD” (p. 1564). Successful prevention strategies seem to combine a mixture of approaches that control or support the internal and external factors of the individual (May 1995). Therefore the objectives of the comprehensive prevention program are to supply “overlapping levels of reinforcement (education and persuasion), incentives, and controls to prevent ARBD” (May, 1995, p. 1563).

Most comprehensive prevention initiatives are based on the public health model, which attempt to impact the health problem on three different levels: environment, agent, and host of the problem (MacMahon & Pugh 1970). However, some believe that utilizing the disease model for complex social problems such as alcoholism may not be helpful for either understanding the myriad behaviours or designing successful prevention strategies (Illich, 1976). Accepting the disease model may narrow the perspective, thus obscuring potential prevention initiatives (Beauchamp, 1980). As well, sociocultural and daily variables may be overlooked (Peele, 1989).

Typically, public health initiatives, or the public health model, are twofold: First, programs work to encourage large numbers of people, communities, and others to modify both individual and major behaviour patterns (May, 1995). Second, programs are intended to support individuals through modifications in the agent, society, and environment (May, 1995). Interventions may include institutions that can influence change such as economic, educational, and religious organizations (Bloom, 1981).

Most prevention initiatives include complex health and social programmes designed to deal with the most difficult problems. Generally, these long-term goals are ambitious and take longer to get established and evaluated than the time allotted (Mackenzie et al. 2007). Long-term funding is essential for policy to evolve "from a tangential role in government to core activity status" (Brantingham et al., 2005, p. 282). Therefore, embedding prevention initiatives within government ensures continuing funding and legislated mandates for those programs deemed successful (Brantingham et al., 2005).

Due to the need for government accountability, programs and initiatives need to be evaluated. An appropriate evaluation framework for complex, multiple outcome, and multi-partner programs can be derived from *theories of change* (Connell, Kubisch, Schorr & Weiss, 1995). This evaluative methodology attempts to examine the component parts and linkages between the rationale of the proposed activities, the short-term outcomes and procedures, and long-term goals (Mackenzie et al. 2007). For example, the theory of change was used to analyze suicide prevention. This research demonstrated that theory of change could be used to evaluate "horizontal complexity" and explain how different organizations, mismatched agendas, and multiple stakeholders influenced the outcomes (Connell & Kubisch, 1998). The theory of change also acknowledges the stakeholders and partnerships, by addressing whether a policy is plausible, doable, testable, and meaningful (Sullivan, Barnes & Matka, 2002). In other words, this study provided evidence for and reinforced the need to use a multi-level framework, similar to the one provided in this dissertation that will be applied to FASD.

Recently, there has been a movement towards comprehensive, multi-agency policy initiatives. Regardless of the terminology (*community collaborations*, *community coalitions*, *complex community-based interventions*, *community change initiatives*, *neighborhood community initiatives*, or *community building*), the general consensus is "inter-organizational, cooperative, and synergistic working alliances" (Zakocs & Edwards 2006, p. 351). Successfully influencing changes in people's lifestyles is a difficult and complex undertaking, requiring integration at multiple levels including individual, communities, services, and systems (Barnes, Matka & Sullivan, 2003). Therefore with the goal of change, the "community team" can focus on (1) the "place" dimension - change in a particular neighbourhood or geographic area; (2) the "comprehensive" dimension – recognize the desired outcomes that are determined by multiple factors and

require multifaceted intervention; and (3) the “community building” dimension – function with respect and appreciate the ability and contribution of each level (Auspos & Kubisch, 2004).

These *community collaborations* can be accomplished by the establishment of “inter-organizational networks of service providers”, referred to as *network analysis* (Barnes, Maclean, & Cousens, 2010). Network analysis offers the potential to consider an individual’s patterns in the context of small groups or sociometric networks (Friedman & Aral, 2001). As well, theory of network analysis identifies the presence of central hubs, exemplified by lateral and horizontal patterns of activity representing collaborations with organizations and agencies, indicating the level of power in the network (Barnes et al., 2010). The response to a social problem is based on an assessment of the multiple determinants and the execution of multilayered strategies focusing on multiple high risk populations (Zakocs & Edwards 2006).

While many believe that collaborations may be a good idea, some consideration of the issues involved needs to be addressed. Policy implementation can be affected by numerous factors including the nature of problem itself, “the circumstances surrounding them [the factors], or the organization of the administrative machinery in charge of the program” (Pal, 2006, p. 191). In addition, bureaucracy plays a significant role in policy implementation. A number of different levels of governments and multiple bureaucratic agencies are involved in implementing policy, each with its own ambitions, interests, and traditions, all affecting the implementation process and the shape of the outcomes (Bardach, 2000).

Influential groups can also affect policy by supporting or opposing the implementation initiative, as well as altering levels of public support. Generally, regulators can collaborate with the groups, even using their resources, to simplify implementation and lessen expenses (Howlett & Ramesh, 2003). Because implementation is generally expensive, it is dependent on persistent negotiations between politicians, agencies, and other subsystem members (Howlett & Ramesh, 2003). Social and economic contexts may also affect the interpretation of the problem, and hence the approach by which long-term programs are implemented (Hutter & Manning, 1990). Following a policy implementation, a decline in support occurs while

the outcome is awaited, which creates an opportunity for administrators to alter the original goal of the initiative (Hood, 1983).

Furthermore, the characteristics of the target group are also an issue. The size of the target group influences administrative discretion. Generally the larger and more diverse the target group, the more difficult it is to alter its behaviour in the desired manner (Pal, 2006). Also, the anticipated degree of behavioural change of the target group affects the difficulty in implementation of the policy initiative (Howlett & Ramesh, 2003).

Researchers now acknowledge that social phenomena such as FASD are created by contingent and intricate processes, requiring appropriate methodology to accommodate these complexities (Hilgartner & Bosk, 1981). From past experience, we know that approaches that focus on specific individuals or problems (piecemeal or categorical approaches) do not achieve the desired outcomes. Therefore, a comprehensive integrated model conceptualizing community change utilizing collaborations may be the answer, resulting in feasible, appropriate, and successful policy implications.

However, the first step is to develop valid and reliable measures of the concepts in the framework. Second, "more work needs to be done in conceptualizing and ultimately testing social change theory that links the concepts in the framework to health outcomes" (Kegler, Twiss, & Look, 2000, p. 775). And finally, "the relationships between the concepts in the framework warrant exploration" (Kegler et al., 2000, p. 775). Hence, one goal of this dissertation is to present a delivery model to demonstrate the complexities, health outcomes, and community collaborations using FASD as a case study. A tri-level policy paradigm will be implemented to provide an organizational framework to understand the problem, to present evidence where possible, to identify gaps in the knowledge, to highlight and evaluate exemplar initiatives, and to recommend future research and policy directions.

Chapter 3.

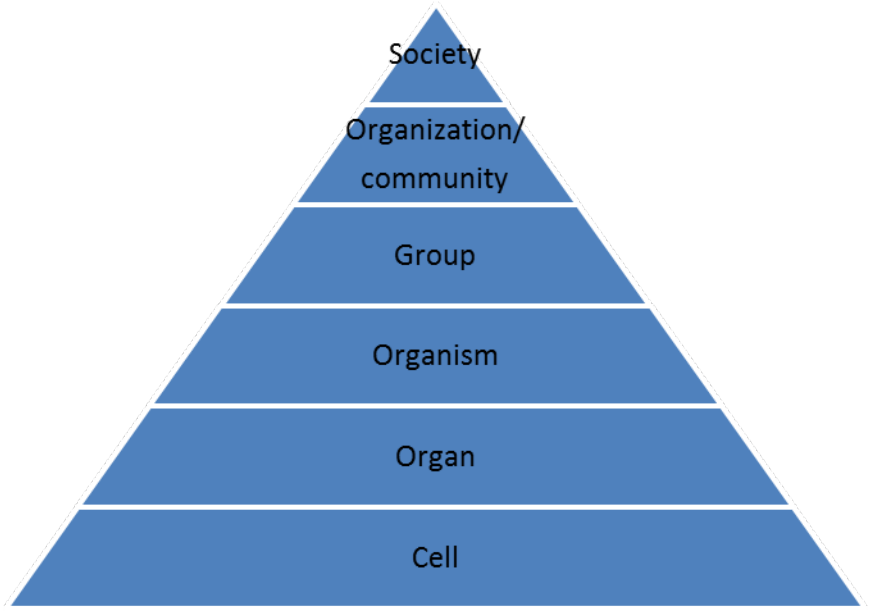
Methods and Methodology

In this chapter, I explain the methodologies and rationale utilized for the data collection and analysis. I begin with a discussion of an integrated systems theory approach, Robinson's model (Robinson, 2004), which will be referenced throughout. I include a discussion on the challenges of acquiring data on individuals diagnosed with FASD and provide a description of each of the available data sets, organized by appropriate prevention level, that were used in this dissertation.

Robinson's Model Applied to FASD

For each of the three levels of prevention, an integrated systems approach, which allows various factors, regardless of discipline, to be discussed and meaningfully integrated into a coherent theoretical explanation of behaviour (Robinson, 2004), will be used. Rather than simple additive logic, the integrated systems model uses interactive logic, requiring the investigator to "think in terms of the mutual interdependence of variables rather than in terms of linear causation and influence" (Jeffrey, 1990, p. 25). This approach is based on the premise that behaviour is the result of "continuous, mutual influence of changing systems of organisms and the environment at many levels of analysis" (Robinson, 2004, p. 39) (See Figure 3.1). In keeping with this organic view, the integrated systems approach refers to varying interactive levels of variables as "the cell level, the organ level, the organism level, the group level, the organization/community level and the society level" (Robinson, 2004, p.38).

Figure 3.1. Robinson's Integrated Systems Approach Illustrated in a Hierarchical Arrangement



The arrangement in Figure 3.1 is appropriate for illustrating the hierarchical requirements, as well as a simplified version of complexity of an individual affected by FASD. If there is a healthy foundation (in this case, the cell level) then one can proceed to the next level (organ level) and continue on with each subsequent level. If there is a "disease" or dysfunction at the foundation (in this case, at the cell level of an individual affected by FASD), then this will affect all subsequent levels.

Cellular Level

The cell is the basic structural unit for all living things. Cells are the building blocks of multicellular organs and can coordinate specialized functions such as the brain or even entire organisms, including humans (Robinson, 2004, p. 53). Although the cell appears to be the foundation, it comprises a number of vital components including genes, neurotransmitters, enzymes, and hormones.

The cell, being the repository of the genetic coding, can regulate which genes are present and can lead to particular traits such as low levels of empathy, IQ, self-control, and fear. And although genes "do not determine medical and behavioural conditions…

they increase or decrease the likelihood that we will develop a medical or behavioural condition" (Robinson, 2004, p. 54). Research also indicates that genes may be involved in mental illness such as schizophrenia and bipolar affect disorder, learning disabilities including dyslexia, and behavioural problems (Robinson, 2004).

At the cellular level, one may find a predisposition for drug dependence. Research shows there is a strong link between genes and drug use. In addition, research has discovered genetic protective factors including alcohol dehydrogenase and susceptibility to alcohol teratogenesis. Therefore, the cell level which mainly represents the effects of genetics and epigenetics,[13] is vital for understanding human behaviour.

Organ Level

The organ level, which is composed of cells and builds on the genetic coding, is the second level of the system. An organ of primary concern in this study is the brain. As Robinson (2004) states: "Any theory of behaviour, including antisocial behaviour and criminality, which includes individuals affected by FASD, is logically incomplete if it does not discuss the role of the brain in behaviour" (Robinson, 2004, p. 72).

Some functions of the brain, vital to the organism's behavioural and cognitive capabilities, are preformed through the brain's system of neurotransmitters. "Neurotransmitters are believed to underlie literally all perceptions, thoughts and forms of behaviour including learning, memory and movement" (Robinson, 2004, p. 80). In addition, the brain coordinates a number of vital functions such as regulating emotion, mood, hunger, thirst, and sleep (Fishbein, 2001, p. 30). The individual's behaviour is

[13] *Epigenetics* is the study of changes in gene expression, caused by mechanisms other than changes in the underlying DNA sequence, in this case, prenatal ethanol exposure. The epigenetic effects "are mediated by modifications that alter the accessibility of DNA to the transcriptional machinery, such as histone acetylation and DNA methylation, or that alter the stability of transcripts, such as RNA interference" (Lin, 2013, p. 22). Recent research indicates epigenetics can affect three generations: the mother (first generation), the fetus (second generation), and reproductive cells (third generation) (Chudley, 2013).

dependent on the health and/ or wholeness of the brain; therefore, it is imperative that the brain is healthy for proper functioning.

Implications of the Cell and Organ Level on FASD Policy Design

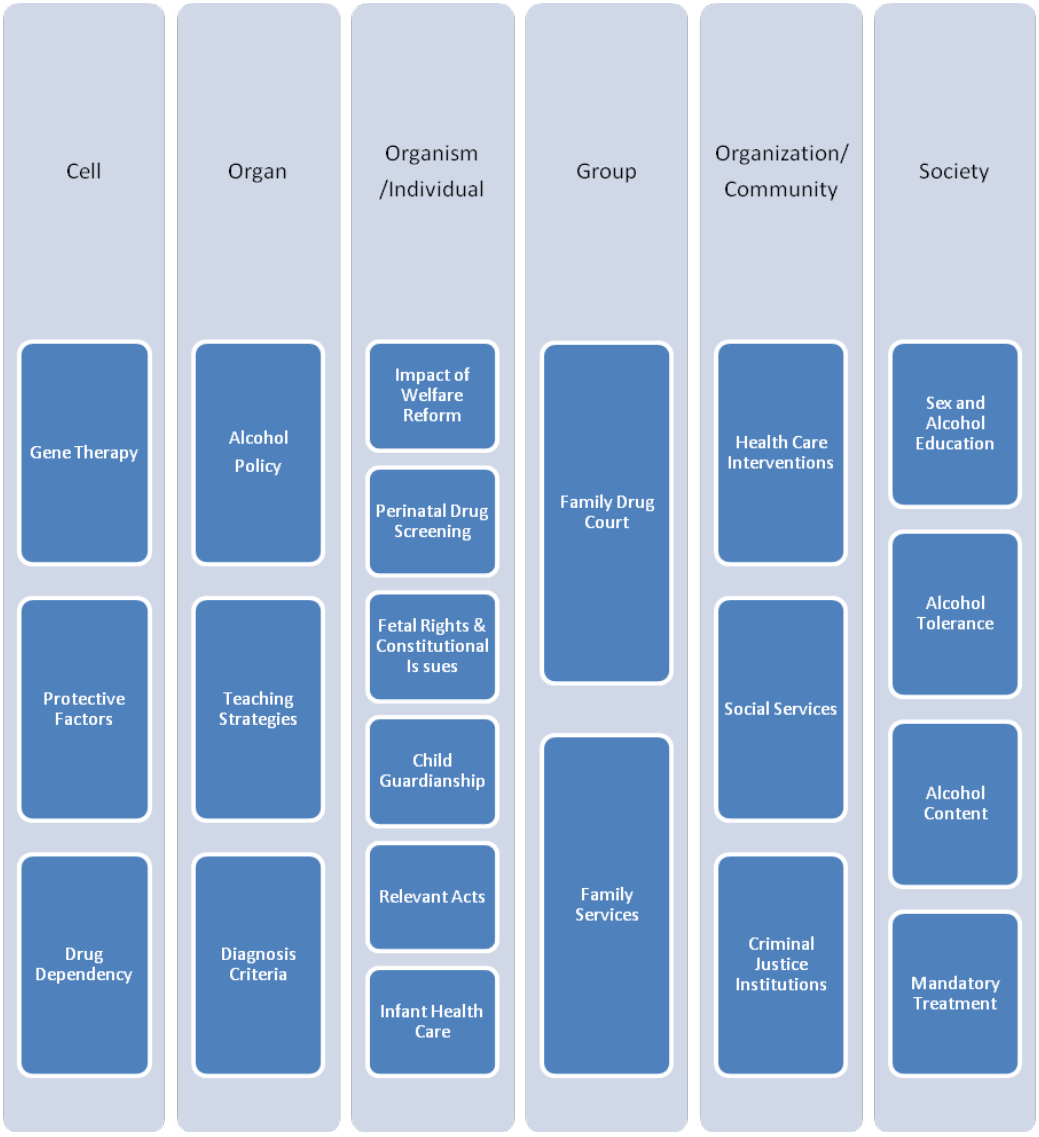
From an understanding of the first two biological levels and the mechanisms involved in FASD, feasible and appropriate policy initiatives can be developed and implemented. Current policy initiatives related to – and affected by – these levels include alcohol policy, teaching strategies, and diagnosis criteria (Figure 3.2). In order for educational strategies to be of any use, the capabilities of the individual affected by FASD must be determined. Assessment may include determination of organic brain injury, medication, and hypoxia. Medication is very important as Ritalin (methylphenidate) and other psychotropic drug regimes are commonly prescribed for individuals affected with FASD. In addition, substance use onset or the individual's predisposition for drug dependency is a concern.

Cognitive processes including IQ, language, executive functioning, and academic skills are all dependent on the foundation of the brain; if the foundation is healthy everything above is healthy, if there is dysfunction in the underlying layers (cells and organs) then there will be dysfunction in the upper levels. Psychopathy, as well as ADD and ADHD, are related to the dysfunction of the brain and can result in behavioural deficiencies.

In relation to designing and measuring policy initiatives, one of the major advantages to this second level is that brain function or dysfunction can be measured by scientific instrumentation such as MRI and neurotransmitter levels, providing real empirical evidence (Raine, 1993). Therefore, the success of objectives and goals for treatment or change at this level can be objectively determined using a logic model.[14]

[14] A *logic model*, also known as *theory of change*, is a depiction of how an activity, in this case, a diagnosis, is intended to produce expected results (Rogers, 2005).

Figure. 3.2. Policy Initiatives Placed within Robinson's Framework for Organization. [15]



[15] This is a very simplified illustration. Each policy initiative 'cell' is made of up multiple parts. The initiative is found in the lowest level of the hierarchy where alcohol has caused an affect; however, it can be found at all higher subsequent levels as well.

Organism (Individual) Level

At the level of the individual, factors include characteristics that are unique to individuals such as "personality traits, intelligence levels, mental illness, diet and nutrition, and drug consumption" (Robinson, 2004, p. 100). For example, personality traits such as disposition, temperament, temper, and character impact and affect behaviour. At this level, the interaction between environment and biology is extremely evident. For instance, disposition and temperament are innate in nature, whereas temper and character are related to culture through experience and learning.

In addition, deriving from the factors at the organ level, cognitive processes and antisocial behaviour are important at the individual level. Healthy executive functioning is a protective factor against delinquency (Robinson, 2004), but is also an ability that is commonly disrupted in an individual affected by FASD. Individuals' developmental factors are also critical at this stage. Dysfunctions of development, such as effects of low birth weight or small head circumference, affect cognitive processes.

Most policy initiatives are related to the individual level, whether they are aimed at the high risk woman or the individual affected by FASD.[16] Such initiatives include welfare reform, perinatal drug screening, fetal rights and constitutional issues, diagnoses criteria, alcohol policy, foster care/border/abandoned babies and adoption, and Safe Families' Acts. In addition, many of these policies focus on the infant, such as seen in vulnerable infants programs, respite care for infant development assessment, and therapeutic nursery psychiatric day treatment for children. The child[17] is also included in initiatives aimed at family groups, family court, parent-child interaction therapy as well as in the parenting education. Ideal interventions related to the child would include the provision of a stable home with nurturing parents and minimal changes in the household;

[16] The initiative is found at the lowest level of the hierarchy where alcohol has caused an affect; however implications can be found at all higher subsequent levels.

[17] The child is considered an individual but provides the foundation for the next level, affecting the group (family) level.

however, at least minimum standards such as protection from violence, either from being witness to or being victimized by violence, have to be met (Kellerman, 2002).

Group (Family) Level

A *group* is “a number of individuals assembled together or having some unifying relationship” which may include family members, peer groups, religious groups, and schools (Robinson, 2004, p. 142). When there is significant alcohol consumption evident within this group, it has a profound impact on female drinking (May et al., 2004).

Limited research exists on the paternal influence specific to FASD, but the few studies there are suggest that fathers of FAS children abuse alcohol and that paternal drinking is related to a small but significant decrease in infant birth weight (Abel, 1990). Although paternal drinking has not been directly related to fetal development problems such as FAS or related diagnosis; some types of alcoholism are very heritable, as well as paternal drinking can damage sperm and has strong social and psychological influences on maternal drinking, which then leads back to Robinson’s first level, the cellular factors contributing to FASD. (May, 1998). Abel (1990) reported close contact with men who are heavy drinkers and who are multiparious increases maternal risk for drinking during pregnancy.

In addition, families may have chaotic and dangerous lifestyles, have a history of childhood sexual abuse, and have involvement in difficult or abusive relationships with male partners. These issues will have to be dealt with also if the individual is to become more functional at this level. All of these factors contribute to the environment of the individual affected with FASD.

Policy initiatives at this level may include family and drug court and interactive therapy, such as parent-child interaction therapy and parenting therapy. It has been realized that for successful initiatives, the interaction of the affected individual, family members, and support need to be understood and incorporated; however, gaps still exist. Despite the progress that has been made at this level, there are many aspects of the development and delivery of programs that needs to be addressed. For example,

there still remains a lack of training and support for caregivers of children affected by FASD.

Community/Organization Level

The second highest organizational level in Robinson's integrated systems approach is the *community* or *organization level* (Robinson, 2004, p. 182). Initiatives at the community or organizational level should include public health programs, foster care/ adoption programs, an environment less supportive of any heavy drinking, the promotion of other positive initiatives that uphold the value of human life and health, safe pregnancy practices, promote socio-economic improvement and access to achievement, education, and employment.

This level's policy initiatives incorporate all previous levels. For example, research indicates that "child abuse and neglect co-exist with parental alcoholism, drug problems and other inadequate social and family functioning" (Robinson, 2004, p. 232). Therefore, if brain injury was sustained from physical abuse, it may cause attention deficits, learning disorder, and poor school performance (Windom, 2000).

Using Robinson's model, high risk females, along with their partners, should be identified, with mandated referral to alcohol treatment and subsequent case management of the women, partners, and children. It is at this level, that conditions of social disorganization within the community (e.g. lack of resources), the effects of routine activities of the affected individual, the individual's lifestyle, and the consequence of labelling are all evident.

Society Level

Societies are made up of communities: "An enduring and cooperating social group whose members have developed organized patterns of relationships through interaction with one another; a community nation, or broad grouping of people having common traditions, institutions, and collective activities and interests" (Robinson, 2004, p. 221). Although every society has a unique social structure, it symbolizes the main

features that determine how the society functions as a whole, which may include institutions and cultured practices (Robinson, 2004).

As the society concepts build on principles established in previous levels, other factors compound the problem. Certain societies or groups may have less contact with positive role models and less access to organized and controlling institutions, such as regional centers (Robinson, 2004). Therefore, these regions or isolated communities may be structurally disadvantaged including "poverty, family disruption, [and] poor health care" (Robinson, 2004, p. 245).

Policy initiatives at the society level include alcohol policy, relevant statutes, sex education, drug courts, fetal rights, mandated referral to alcohol treatment, and case management for high risk women and children (Figure 3.2). In addition, it includes those activities that promote other positive initiatives that uphold the value of human life and health and safe pregnancy practices, such as promoting lower alcohol content in beverages. Also, those which promote socio-economic improvement and access to achievement, education, and employment are to be included.

By using Robinson's Integrated Systems Approach to organize the factors at each level, one can gain an understanding of the complexity of issues related to individuals affected by FASD. This model also illustrates how everything interrelates and gaps become evident, hence, identifying areas where initiatives can be implemented. In addition, with this approach, it becomes possible to visualize ways to manage FASD at multiple levels, throughout the life course of the individual.

Data Sources[18]

Despite numerous attempts to obtain available data to demonstrate evidence-based initiatives and promises from two governmental agencies that I would have

[18] Data will be used as appropriate, for each of the three levels: the tertiary, the secondary, and the primary.

access to case files, after years of waiting, no data were made available to me. As an academic researcher, I acknowledge and respect the sensitive nature of the information contained in personal files, particularly of those who are considered high risk for FASD. There are, however, ways of making such information anonymous so that confidentiality can be maintained and the data requested, which would be useful for developing evidence-based policy initiatives, can be accessed. In addition, many researchers and professionals have databases for their specific purposes; these could be aggregated into useful characteristics and scenarios, while adhering to privacy issues by protecting identifiers and, in this way, contributing to the gaps in knowledge and providing data to evaluate "more promising" initiatives.

As there are currently very limited raw data on individuals with FASD available, analysis, it seems, must be conducted only by "ad hoc" or "proxy" measures. Although this dissertation makes an argument for the use of "available" and "piecemeal" data to support existing literature, it acknowledges limitations of this type of inference.

Tertiary Level: Individuals Affected by FASD

The tertiary level refers to those individuals with FASD. Due to the secondary disabilities associated with FASD; it is not uncommon for these individuals to be found within the criminal justice system. This section analyzes data from the Incarcerated

Serious and Violent Young Offenders Study[19] as well as from legal cases found within the CanLII[20] database.

Analysis of Serious and Violent Young Offenders Data

Sample

The Study on Incarcerated Serious and Violent Young Offenders originated in 1998 with the purpose of understanding risk factors associated with serious criminal offending in youth. Originally data were collected from over 500 youth incarcerated in secure and open custody facilities. In addition to data obtained from interviews, official file reviews were conducted. The official file data were provided by the Ministry of Child and Family Development (MCFD) and contained information on offence history, current criminal offence, and risk factors including family history, education, special needs, mental health concerns, substance use, and victimization. Online file information including CORNET data was provided by MCFD for these participants. The ultimate goal of this study was to collect information to assist the MCFD in reducing and preventing recidivism in serious and violent offenders by developing evidence-based policies, programs, and practices (Freedman & McCormick, 2011).

The data presented in this dissertation are derived from a subsample[21] of serious and violent offenders who were interviewed between 2005 and 2011 in open and secure

[19] Special permission was given by Dr. Ray Corrado, the principal investigator of the project to access data. Original permission was granted "by the Ministry of Children and Family Development, who represented the youth's primary caregiver during incarceration," as well as Simon Fraser University's Ethics Review Board (McCuish, 2012, p. 43).

[20] CanLII (Canadian Legal Information Institution) database consists of case law and legislation from across Canada. The search criteria include only cases from British Columbia Courts (Court of Appeal, Supreme Court of British Columbia, and the Provincial Court of British) and nine Boards and Tribunals. For complete inclusion criteria for the CanLII database and contributing sources see http://www.canlii.org/en/databases.html. Cases containing FASD, ARND, and FAE were retrieved June 27th; whereas FAS cases were retrieved July 26th, 2013. All Court of Appeal and Superior Court Cases were retrieved August 13th, 2013.

custody facilities within British Columbia (McCuish, 2012). The sample consists of 517 youth, who range in age from 12 to 18 years, with a mean age of approximately 16 years (McCuish, 2012).

The Serious and Violent Young Offenders data present a unique opportunity to analyze individuals affected by FASD who, due to the associated disabilities, are commonly found in the criminal justice system (Fast & Conroy, 2009). The first goal of this research is to provide an analysis of the characteristics found in these individuals clinically diagnosed with FASD. The second goal is to contribute to the existing Canadian context for serious and violent incarcerated youths with FASD.

Research Questions and Hypotheses

The goals of this research are addressed by the following research questions and hypotheses.

1) What are some of the relevant demographic statistics of the serious and violent young offenders incarcerated in secure and open custody facilities within the province of British Columbia?
2) What is the demographic profile of the serious and violent young offenders clinically diagnosed with FASD incarcerated in secure and open custody facilities within the province of British Columbia?
3) Does a clinical diagnosis of FASD influence negative life outcomes?

These research questions are important because they are directed at obtaining a more complete understanding of FASD in general and, more specifically, of incarcerated serious and violent offenders, which include individuals with FASD due to their secondary disabilities. The analysis presented provides information relating to the

[21] Though considered a subsample as the data collection and entry are ongoing, this group will, however, be referred to as *the sample* throughout this dissertation (McCuish, 2012).

characteristics mentioned in most of the literature on individuals affected by FASD who are found in the criminal justice system. Hence, I assess the relationships of FASD on negative life outcomes.

Hypothesis 1: Youth with a clinical diagnosis of FASD have a greater likelihood of early onset of aIcohol use, daily alcohol use, early onset of drug use, daily drug use, physical abuse, sexual abuse, being kicked out of home, foster care placement, being adopted, intimidating or bullying; and having affect disorder (schizophrenia or psychosis) or behavioural disorders.

Hypothesis 2: Youth with a clinical diagnosis of FASD have a strong and significant correlation with a negative permissive environment, increased criminal versatility, increased substance use versatility, negative identity, low self-control, and poor behaviour in school.

Hypothesis 3: Youth with a clinical diagnosis of FASD have significantly higher mean scores on permissive environment, criminal versatility, substance use versatility, negative identity, low self-control, and poor behaviour in school.

Measures of Independent Variables

The measure for *Gender* is coded (male = 0; female = 1) by the researcher at the time of the interview. *Ethnicity* was determined by the respondent answering (0 = Caucasian; 1 = Aboriginal; 2 = Other) to the question: “Describe the ethnic group you feel most a part of”. The respondents were asked whether or not they had ever been *clinically diagnosed with FASD*, and the diagnosis was verified through file review (*no* = 0; *yes* = 1). If the participant self-reported a diagnosis and the file information did not support it or vice versa, the response was reported as *no*. The measure of *age* was determined by the age of the participant at the time of the interview.

Measures of Dependent Variables

There were two measures of substance abuse/use. *Early onset of alcohol use* was determined by offender’s response (*no* = 0; *yes* = 1) to whether they drank alcohol

before the age of 12, and the participants' self-reported response (*no* = 0; *yes* = 1) to using drugs before the age of 12 determined the *early onset drug use* variable. *Daily alcohol and drug use* was determined by the offenders' response (*no* = 0; *yes* = 1) to whether they drank alcohol or used drugs daily.

There were two measures of abuse. The *physical abuse* measure was determined by the offenders' response to "have you ever been physically abused?" (*no* = 0; *yes* = 1). Whereas sexual abuse was determined by the response to "has anyone ever forced you to do sexual things that you didn't agree to?" (*no* = 0; *yes* = 1). These responses were confirmed by official file information. If any discrepancy existed between the responses, the youth's case management file would be used.

A number of measures relate to the living conditions of the offender. The measure *ever been adopted* was determined by the offenders' response to "have you ever been adopted" (*no* = 0; *yes* = 1). *Foster care placement* was determined by self-reported lifetime involvement with child services (either foster care or adoption) (*no* = 0; *yes* = 1). The variable *kicked out of home* was determined by the offenders' response (*no* = 0; *yes* = 1).

The measure *affect disorder* was determined by the offenders' self-reported belief or diagnosis of *affect disorders* such as depression, PTSD, anxiety, bipolar, suicide, ideation, and eating disorder (*no* = 0; *yes* = 1). This response was confirmed with official file information. *Schizophrenia and psychosis* was self-reported by the offender as *no* = 0 or *yes* = 1, which was confirmed by official file information. The measure *behavioural disorder* was determined by the offenders' self-reported belief or diagnosis of having a learning disability, obsessive compulsive disorder, antisocial personality disorder, attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD), conduct disorder (CD), or oppositional defiant disorder (ODD) (*no* = 0; *yes* = 1). This response was then confirmed with official file information. For all of the above variables, if a participant self-reported a diagnosis and the file information did not support it or vice versa, the response would be reported as *no*. The *bullying* measure was determined by self-report responses to the question: "Have you ever been in trouble at school for intimidating or bullying other students?" (*no* = 0; *yes* = 1).

A composite measure for *permissive environment* was constructed from 10 dichotomous items that assess the prevalence of a negative social environment[22] (Cronbach's alpha[23] = 0.690). The composite consists of whether the youth answered (no = 0; yes = 1) to each of the items: biological mother's and father's drinking problem, biological mother's and father's drug use, biological mother's and father's exposure to physical abuse, biological mother's and father's exposure to sexual abuse, and biological mother's and father's criminal record.

The literature indicates that individuals with FASD develop a number of secondary disabilities as they mature. These dependent variables were analyzed. A composite measure of c*riminal versatility* was constructed from 14 dichotomous items (Cronbach's alpha = 748). The individual items are breaches, trafficking, car theft, stalking, theft from person, theft from household, threatening, assault with weapon, robbery, murder, attempted murder, manslaughter, and criminal negligence causing death.

Versatility of substance use was a 14-item scale that assesses the prevalence of substance use determined by self-reported answers to ever using alcohol, marijuana, glue, gas, demerol, valium, prescription pills, morphine, mescaline, opium, ecstasy, heroin, cocaine or crack cocaine, methadone, and/or crystal meth (*no* = 0; *yes* = 1). This composite seems to accurately represent *substance versatility* (Cronbach's alpha = 0.789).

A composite measure of *identity* was constructed from 15 items (Cronbach's alpha = 0.748). The individual items are based on A.L. Schneider's Good Citizens Scale used for measuring the youth's self-reported perceptions of their identity. The composite consists of how the youth rates themselves on a scale from 1 to 7, where only positive items would score a 1; therefore lower scores would indicate negative self-identity. The

[22] Literature dictated items that were included in the composite *permissive environment*, and the combination of items with the best Cronbach's alpha score was selected for the analysis.

[23] Cronbach's alpha is a measure of internal consistency of a scale, which "describes the extent to which all the items in a test measure the same concept or construct" (Tavakoi & Dennick, 2011, p. 53). Alpha is expressed as a number between 0 and 1, whereas acceptable values range from 0.70 to 0.95 (Bland & Altman, 1997; Tavakoi & Dennick, 2011).

items include: (1) troublesome/cooperative, (2) bad/good, (3) breaks rules/obeys rules, (4) rude/polite, (5) harmful to others/helpful to others, (6) cowardly/brave, (7) dumb/smart, (8) dishonest/honest, (9) lazy/hardworking, (10) weak/tough, (11) wild/not wild, (12) mean/nice, (13) cruel/kind, (14) poor/rich, and (15) unattractive/attractive.

A composite measure for s*elf-control* was constructed from 14 dichotomous items (Cronbach's alpha = 0.670). The individual items relate to risk taking, temper, and preference for physical rather than cognitive processes.

A composite measure for *behaviour in school* was constructed from 15 dichotomous items that assess the prevalence of negative behaviours (Cronbach's alpha = 0.796). The individual items are cheating, being impolite, being late, skipping a class, skipping the day, bullying, fighting, hitting student, hitting teacher, being drunk, being high, using alcohol, using drugs, selling alcohol, selling drugs, in possession of a weapon, selling weapon, stealing, and inappropriate sexual touching.

Analytic Strategies

Chi-square tests using IBM SPSS Statistics 21® were conducted to examine the associations between developmental factors including demographics, substance use, living circumstances, and mental illness, in relation to a clinical diagnosis of FASD. *T*-tests were conducted to determine if there are differences between population means for permissive environment, criminal versatility, number of substances used, self-control, identity, and behaviour at school, and a clinical diagnosis of FASD. In addition, Correlation Pearson's *r* was utilized to further describe significance and strength of relationships of these variables.

Examination of CanLII Database

The second source of available data containing individuals with FASD was CanLII, where exemplar cases were extracted using search parameters consisting of the Province of British Columbia, no date restriction, although cases occurred between1994 to 2013, and the following key words: *FASD*, *FAS*, *FAE*, and *ARND* (Table 3.1). These results will be repositioned within the existing literature on individuals affected by FASD.

Table 3.1. Selection of Exemplar Cases from CanLII Database.

Search Terms	Number of Cases	Irrelevant Cases
FASD	23	1
ARND	13	0
FAS	85	32
FAE	44	14
Irrelevant Cases*	47	
Duplicates**	53	
Total	65	

*Examples of irrelevant cases include cases with the last name: Fa, Fae or Fas; acronyms such as FAS Seafood Producers Ltd; and British Columbia Human Rights Tribunals that refer to a Functional Abilities Evaluation form (FAE). ** Duplicates refer to those cases that used multiple key words such as "either FAS or ARND" or "FAS/FAE."

Secondary Level:
High Risk Women Calls for Service for Child Welfare Code

For this level, Police Information Retrieval System (PIRS) data were used to examine its dimensions. PIRS constitutes the RCMP calls for service records, in which individual names have been removed and the data are aggregated to non-identifiable levels before being released.[24] These records are complete for the province of British Columbia, between August 1, 2002, and July 31, 2006, and identify all police contacts, providing home locations of individuals, information about the contact occurrence, and dates and times of the encounter (Wuschke & Huitson, 2010, unpublished). For the geographical basis of the analysis, a spatial layer identifying all police detachments will be incorporated.

[24] Released into ICURS, the SFU Institute for Canadian Urban Research, a secure lab, where access is only accessible to security cleared researchers. The data collected for this dissertation adhere to the MOU with the RCMP as well as the Research Ethics Board at SFU.

The PIRS data base was searched for police contacts that involved the Child Welfare Act (AG0001)[25] resulting in a total of 6999 calls for the 4-year period.[26] Although this code doesn't guarantee that the individual interacting with police has FASD, it is likely that it is associated with high risk females who have many of the contributing social factors affiliated with FASD[27] (Table 3.2).

Table 3.2. List of Top 20 B.C. Detachments Based on Use of Child Welfare Code.

Rank	Detachment	Total Calls Generated by AG0001 code
1	Lower Mainland 1	642
2	South East 1	471
3	Island 1	425
4	Fraser Valley 1	367
5	Island 2	238
6	North 1	236
7	Lower Mainland 2	227
8	Island 3	224
9	Lower Mainland 3	208
10	Lower Mainland 4	199
11	South East 2	190

[25] When children or youths are involved and are perceived to be endangered, police have the ability to remove them from the environment under the Child Welfare Act; hence the caregiver will be the subject of the case. As well, if a child or youth who is placed within a foster home does not abide by the established criteria, she being the subject of the case will also be removed from the home using the code crime AG0001.

[26] Specific query for police contacts with intoxicated females in B.C. using the Child Welfare Code:
Select * from DBEAOWN.EVENT_002 E, DBEAOWN.SUBJ_002 S
where E.date_from between '20020108' and '20060731' and E.ori_crime_code='AG0001' and S.gender = 'F' and (E.ori_detachment='BC20001' or E.ori_detachment='BC20006' or E.ori_detachment='BC20014') and E.ori_detachment=S.ori_detachment and E.occ_occurence_number=S.occ_number and E.volume_location=S.volume_location_subject group by E.ori_detachment

[27] Preliminary analysis on data from the Study on Serious and Violent Incarcerated Youth indicate that almost 87% of the individuals who have foster care placement have been diagnosed with FASD, which suggests the use of this data for this exercise is appropriate. Keeping in mind, the intent of this exercise is to contribute to further information regarding characteristics of this high-risk population.

Rank	Detachment	Total Calls Generated by AG0001 code
12	Island 4	187
13	Lower Mainland 5	183
14	North 2	181
15	Island 5	176
16	South East 2	163
17	Island 6	160
18	North 3	150
19	Lower Mainland 6	114
20	Lower Mainland 7	114
	Total in BC	6,999

This database also contains social factors including age, occupation, location of residence, number of contacts with police within the specific period, reasons for contact with police, and other police involvement at the listed residence – all of which may give an indication of violence, alcohol abuse, and so forth, and reinforce some of our current knowledge on contributing factors to FASD. Three exemplar cities were selected from the top 20 B.C. detachments with the highest number of cases involving the Child Welfare Code. These represented City A (a Lower Mainland city), City B (an interior city), and City C (a northern city), respectively. Common characteristics and themes will be identified and compared from the cases within each of the selected cities and discussed further in detail in Chapter 6.

Primary Level:
Locations of Medical Services Available & Alcohol Use

The PIRs database allows for spatial analysis, where the data were explored to determine the overall trends of police contacts with intoxicated females throughout the

province. The exploration took place through database queries using IBM's DB2 program.[28]

Specific to the primary level exercise demonstrating the juxtaposition of medical facility locations versus police contacts with intoxicated persons, a final spatial layer was required. This file contained all hospital and health service locations within the province. "This layer is accurate as of 2005, fitting with the timeframe of the calls for service dataset, and is provided by DMTI Spatial" (Wuscke & Huitson, 2010, p. 4, unpublished).

"In order to geographically analyze all RCMP calls for service associated with the [specific queried criteria], each record needs to be given a spatial reference. This process normally involves geocoding - providing a spatial coordinate to each record, based on the address of the home [or crime] location and a road network" (Wuscke & Huitson, 2010, p. 4, unpublished). Wuscke and Huitson (2010) discuss problems with this technique but provide initiatives to ensure the best accuracy and validity possible with the available data.

The final stage of this exercise is intended to explore the locations of health services across the province in relation to the location of calls for service regarding intoxicated females. As reported by Wuscke and Huitson (2010, p. 5, unpublished), "the locations of hospital services were overlaid on top of the spatial distribution, in order to provide a visual representation of health services access". The results identified in this exercise will be further discussed in Chapter 7.

In this chapter, I have explained the methods and underlying principles for the data collection and analysis. I introduced Robinson's model, an example of an

[28] Specific query for police contacts with intoxicated females in B.C.:
Select * from DBEAOWN.EVENT_002 E, DBEAOWN.SUBJ_002 S
where E.date_from between '20020108' and '20060731' and (S.stat1='0022' or S.stat2='0022' or S.stat3='0022') and S.gender='F' and
E.occ_occurence_number=S.occ_occurence_number and
E.ori_detachment=S.ori_detachment and E.volume_location=S.volume_location_subject
group by E.ori_detachment group by E.ori_detachment

integrated systems approach. I provided an exercise of data analysis for each of the three levels of prevention.

Chapter 4.

Discussion: Tertiary Prevention Level

The results and discussion section will be organized into several chapters, each one representing a level of prevention. Robinson's model of organization will be implemented throughout this dissertation where applicable and possible. This chapter introduces the tertiary level of prevention. At this level, the focus is on the individual affected by FASD and the goal is to provide continuous interventions throughout the individual's life, so he or she will "not commit" crimes and can function in the community.

This chapter builds on the literature presented in Chapter 2; however, the focus shifts to the secondary disabilities, the link to criminality, and the rational choice debate. This discussion will be further supported by an analysis of the Serious and Violent Incarcerated Youth database.

I also present preliminary findings from an analysis of legal cases associated with individuals affected or suspected of having FASD obtained from CanLII. These cases illustrate the issues that have emerged as individuals affected by FASD proceed through the criminal justice system. I then provide some direction and context to new program initiatives that attempt to address these concerns.

In addition, I provide a summary of exemplar initiatives and "more promising programs" addressing the "management" of affected individuals, as well as of caregivers, families, and community support programs. I end this chapter with an analysis of the disjuncture in one existing FASD policy.

Serious and Violent Offenders Analysis

Research supports that individuals affected by FASD are disproportionately involved in the criminal justice system due to the complexities of the disability and the limited support and resources in the communities available to them (Fast, Loock, & Conroy, 1999; Morley, 2006). Out of the 517 incarcerated youth interviewed for the study, 11.3% were clinically diagnosed with FASD[29] (see Table 4.1). This finding was surprising low as the disabilities associated with FASD usually do not allow for the individual to abide by the conditions to be released or remain law-abiding in the community.

Table 4.1. Serious and Violent Offender Descriptive Statistics.

		n	**%**
Gender	Males	445	86.6
	Females	69	13.4
Ethnicity	Caucasian	272	53.1
	Aboriginal	163	31.8
	Other	77	15.0
Diagnosed FASD		58	11.3
Early onset of alcohol		207	40.0
Early onset of drugs		228	44.1
Daily alcohol use		72	13.9
Daily drug use		372	73.3
History of substance abuse		362	70.0
History of physical abuse		225	44.5
History of sexual abuse		60	11.9
Ever adopted		40	7.7
Foster care placement		289	56.4
Kicked out of home		310	60.3
Affect disorder		361	70.5

[29] FASD is used throughout this section; however *FAS/FAE* was the terminology used in the original research as it pre-dated the term *FASD*.

	n	**%**
Schizophrenia or psychosis	69	13.5
Behavioural disorders	340	66.5
Intimidating or bullying	294	56.9
	Mean	**Standard Deviation**
Age	15.84	1.315
Permissive environment	2.1344	2.04255
Self-control	6.7146	3.52103
Identity	69.116	10.2948
Criminal versatility	7.7407	2.79333
Number of substances used	5.3191	2.63192
Behaviour at school	9.3569	3.68639

An analysis of the descriptive data collected on these incarcerated youth revealed a disproportionate number of males (87%) and Aboriginals in this incarcerated population. Of the sample, 53% considered themselves Caucasian whereas approximately 32% reported their ethnicity as Aboriginal.

The young offenders in the sample reported high levels of substance abuse. Seventy percent reported a history of substance abuse, with more than 40% of them drinking alcohol and using drugs before the age of 12, 13.9% admitting to daily alcohol use, and 44% to daily drug use.

These young offenders were also exposed to a high level of abuse and themselves perpetrated the abusive behaviour. An analysis of lifetime exposure to physical abuse indicated that 44.5% of the youth experienced one or more instances of physical abuse in their lifetimes, whereas 11.9% of the youth disclosed that they were victims of ongoing physical abuse. In addition, the majority of the youth (57%) interviewed, self-reported intimidating or bullying others at school.

Many of these offenders experienced unstable home environments and conditions that led to changes in their living arrangements. More than half (53.2%) of the participants were not living with parents because they had been kicked out or had chosen to leave on their own accord, 56% spent time in foster care, and 7.7% were adopted.

Mental illness was prevalent in the sample. Approximately 71% suffered an affect disorder, and 13.5% were affected by schizophrenia or psychosis. As well, 66.5% documented behavioural disorders such as learning disabilities, obsessive compulsive disorder, antisocial personality disorder, ADD or ADHD, conduct disorder, or ODD.

Many of these offenders experienced unhealthy and permissive environments where there was substance use, physical and sexual abuse, and where one or more of the biological parents were involved in criminality. Analysis revealed that for the 10-item *permissive environment* index the mean was 2.1344 (*SD* = 2.04255).

Low self control was also prevalent in the sample. A 14-item index that included risk taking, temperament, and preference for physical rather than cognitive processes, the offenders obtained a mean of 6.7146 (*SD* = 3.52103) for this 14-item composite. In addition, the majority of these offenders had a negative view of themselves. The *identity* composite consisted of how the youth ranked themselves on a scale from 1 – 7, 1 being positive for each of the 15 characteristics. The youth had an *identity* mean score of 69.1158 (*SD* = 10.29478).

The young offenders in the sample reported committing a wide range of criminal acts. Analysis of the 14-item index revealed that the mean *criminal versatility* score was 7.7407 (*SD* = 2.79333). In addition, the offenders can be described as poly-substance users in their lifetime; the substances they used included alcohol, marijuana, heroin, cocaine, and crystal meth. Results for substance use indicated that the offenders used a mean of 5.3191 (*SD* = 2.63192).

Many of these offenders exhibited negative behaviours in the school environment. Analysis revealed that for the 15-item composite, offenders self-reported a mean of 9.3569 (*SD* = 3.68639) negative behaviours such as cheating, fighting, being drunk, selling drugs, and possessing a weapon.

In the process of this analysis, differences between the FASD and non-FASD youth within this serious and violent offender population emerged (see Figure 4.2). It became evident that both populations had similar biological and sociological factors that contributed to their criminality and subsequent inability to remain law-abiding. Results indicated that a clinical diagnosis of FASD is not gender-biased, as the percentages of FASD diagnoses were similar in both males and females. However, FASD diagnoses

were more common in Aboriginal youth (54%) compared to those self-reported as Caucasian (46%).

Table 4.2. Comparison of FASD and Non-FASD Serious and Violent Offenders.

	FAS Youth		Non-FASD Youth	
	n	**%[30]**	***n***	**%**
Gender				
Males	49	84.5	396	86.6
Females	9	15.5	60	13.2
Ethnicity				
Caucasian	26	45.6	246	54.1
Aboriginal	31	54.4	132	29.0
Other			77	16.9
Early onset of alcohol	30	51.7	177	39.5
Early onset of drugs	30	51.7	197	43.2
Daily alcohol use	12	20.7	57	12.6
Daily drug use	46	80.7	331	73.4
Physically abused	31	56.4	194	43.0
Sexually abused	9	16.4	51	11.3
Ever been adopted	10	18.2	30	6.6
Placed in foster care	48	85.7	240	52.9
Kicked out of home	36	62.1	272	59.9
Affect disorder	42	72.4	319	70.3
Schizophrenia or psychosis	9	15.5	60	13.2
Behavioural disorders	48	84.2	292	64.3
Intimidation/bullying	35	61.4	258	56.8

Although all the young offenders in this serious and violent population were exposed to high levels of substance use, individuals with FASD indicated more substance use than non-FASD offenders. More than half of the participants with FASD reported early onset drug and alcohol use, meaning substance usage before the age of

[30]Percentage of characteristic present

12. Both groups of youth reported greater daily drug use than daily drinking. As well, more offenders diagnosed with FASD used drugs daily (81%) than individuals not diagnosed (73%).

Besides exposure to substance use, the young offenders affected by FASD were frequently subjected to physical and sexual abuse. More than half of the youth diagnosed with FASD were physically abused compared to 43% of those not diagnosed. Also more individuals affected by FASD were sexually abused than those individuals who did not meet the criteria. Individuals affected by FASD generally misinterpret social cues and have a desire for acceptance, making them extremely vulnerable to abuse.

In addition, there were differences in living conditions between youth affected by FASD and those who were not. Although there was no difference regarding being kicked out of the home, 86% of the FASD youth had foster care placements compared to only 53% of non-FASD youth. Surprisingly, 18% of those youth affected by FASD were adopted compared to 7% of those not clinically diagnosed with FASD.

As well as having poor living conditions, mental illness was prevalent in both groups. Roughly 70% of the youth self-reported suffering from affect disorder such as depression, post traumatic stress disorder (PTSD), and anxiety; whereas 14% disclosed to having schizophrenia or psychosis. However, individuals with FASD were more likely to report behavioural disorders (84%) compared to non-FASD youth. Surprisingly, both FASD offenders and non-FASD offenders revealed similar percentages for intimidating or bullying others: 57% and 61%, respectively.

In the specific context of incarcerated serious and violent offenders, a number of characteristics are related to negative life outcomes. Results indicated that there was a significant association ($X^2 = 20.572$, $df = 1$, $p < 0.001$) between ethnicity and a clinical diagnosis of FASD. Fifty-four percent of Aboriginal offenders were clinically diagnosed with FASD, compared to only 45.6% of Caucasian participants. Individuals diagnosed with FASD were more likely to be Aboriginal than Caucasian.

The results suggested that a clinical diagnosis of FASD was related to living conditions. There was a significant association ($X^2 = 21.886$, $df = 1$, $p < 0.001$) and ($X^2 = 9.075$, $df = 1$, $p < 0.01$) between an FASD diagnosis and the likelihood of being placed in foster care and being adopted, respectively. Almost 87% of FASD offenders were placed

in foster care sometime in their lives compared to only 52.9% of those offenders who did not meet the FASD criteria. Ironically, offenders with FASD were more likely to be adopted (18.2%) compared to those that were not diagnosed (6.6%).

The analysis indicated that a clinical diagnosis of FASD influenced mental health. Results suggested that there was a significant association ($X^2 = 9.001$, $df = 1$, $p < 0.01$) between a clinical diagnosis of FASD and behavioural disorders. More than 84% of offenders affected by FASD self-reported having *behavioural disorders* such as a learning disability, obsessive compulsive disorder, antisocial personality disorder, ADD, ADHD, conduct disorder, or ODD, compared to only 64.3% for non-FASD offenders.

The literature identified a number of factors, including gender, ethnicity, a clinical diagnosis of FASD, and permissive environments, that influence criminal and deviant behaviours. Specifically, criminal versatility, substance versatility, and behaviour at school; as well as interpersonal qualities such as identity and self-control, were analyzed. The results indicated that there was a weak correlation between gender (female) and substance versatility, $r = 0.210$, $p < 0.001$. There was also a weak negative correlation between gender and identity, $r = -0.121$, $p < 0.01$. There was a weak correlation between ethnicity and a clinical diagnosis of FASD, $r = -0.171$, $p < 0.001$. The analysis also demonstrated that there was a negative correlation between a clinical diagnosis of FASD and identity, $r = -0.098$, $p < 0.05$, and a clinical diagnosis and low self-control, $r = 0.113$, $p < 0.05$.

Permissive environment had the most influence on criminal and deviant behaviours. The results indicated that there was a weak correlation between permissive environment and criminal versatility, $r = 0.273$, $p < 0.001$ and substance versatility, $r = 0.259$, $p < 0.001$. It was also weakly correlated to behaviour at school, $r = 0.221$, $p < 0.001$.

Permissive environment also impacted individual characteristics such as low self-control and identity. Analysis indicated there was a weak negative correlation between permissive environment and identity, $r = -0.136$, $p < 0.01$. There was also a weak correlation between permissive environment and low self-control, $r = -0.260$, $p < 0.001$.

The literature indicated that individuals affected by FASD engage in criminal and deviant behaviours and express different interpersonal qualities than individuals that are

not affected. *T*-tests were conducted to assess the mean difference of FASD and non-FASD incarcerated youth on permissive environment, criminal versatility, substance versatility, identity, self-control, and behaviour at school (Table 4.3).

Table 4.3. Comparison of Clinical Diagnosis of FASD and non-FASD Offenders. (SD=standard deviation)

Variables	FASD Mean *(SD)*	Non-FASD Mean *(SD)*	Mean Difference	*T*
Permissive Environment	2.9286 (2.34991)	2.0290 (1.97903)	-0.89962	-3.138**
Self-control	7.855 (3.1530)	6.5708 (3.54344)	-1.28375	-2.566*
Identity	66.281 (10.657)	69.431 (10.1628)	3.15045	2.191*
Criminal versatility	8.3036 (2.7431)	7.6674 (2.8004)	-0.63617	-1.607
Behaviour at school	10.053 (3.7197)	9.2578 (3.6811)	-0.79485	-1.534
Number of substances used	5.7586 (2.940)	5.261 (2.5916)	-0.49766	-1.356

*0.05 significance

** 0.005 significance

Results indicated that individuals with FASD were exposed to a more permissive environment. The analysis demonstrated that there was a significant mean difference of 0.89962 (t = -3.138, df = 505, p <0.005) on permissive environment between offenders with a clinical diagnosis of FASD (Mean = 2.9286, *SD* = 2.34991) and offenders without a diagnosis (Mean = 2.0290, *SD* = 1.97903).

Individuals affected by FASD had lower self-control due to the associated secondary disabilities. Results suggested that there was a significant negative mean difference of 1.28375 (t = -2.566, df = 504, p < 0.05) on lower self-control between offenders with a clinical diagnosis of FASD (Mean = 7.855, *SD* = 3.1530) and offenders without a diagnosis (Mean = 6.5708, *SD* = 3.5344).

In addition, individuals affected by FASD had a more negative outlook. The analysis determined that there was a significant mean difference of 3.15045 (t = 2.191, df = 497, p< 0.05) on negative identity between offenders with a clinical diagnosis of FASD (Mean = 66.281, *SD* = 10.657) and non-FASD offenders (Mean = 69.431, *SD* = 10.1628).

Discussion of Offender Data

It is not surprising that individuals diagnosed with FASD were found within this serious and violent offender population. However, with only 11.3% being clinically diagnosed, this percentage was slightly lower than anticipated and previously reported for a similar population of incarcerated youth (n = 287), with a composition of 22.3% diagnosed with alcohol-related diagnoses (Fast et al., 1999). The difference could be partially explained by the new implementation of the term *FASD* and the associated confusion with the non-visible characteristics of the disease, as opposed to the previous terminology *FAS* and the other alcohol-related diagnoses, which were used in the original study, The Study on Incarcerated Serious and Violent Young Offenders.

The majority of the offenders in this study reported a history of substance use, but there were no relationships between daily use or early onset of either alcohol or drugs and a clinical diagnosis of FASD. This finding does conflict with the literature which has found that individuals affected by FASD typically suffer from drug and alcohol problems (Morley, 2006), though the population studied here was serious and violent offenders who often had similar negative childhood experiences and biological predispositions which have been found to result in individuals resorting to drugs and alcohol to self-medicate or to feel accepted.

More than half of the individuals affected by FASD indicated physical abuse, and 16% reported being victims of sexual abuse. Although this finding is slightly lower than the reported 72% abuse for individuals with FASD (Kellerman, 2002), it is consistent with the disability research which states that these individuals are more vulnerable to crimes involving interpersonal violence (Petersilia, 2001). This study confirms individuals affected by FASD are more often the least capable of recognizing danger, incapable of

protecting themselves, and unable to obtain assistance within the criminal justice system (Peterselia, 2001).

Mental illness seems to be prevalent in the sample. Although there were no significant differences in suffering from affect disorder, schizophrenia, or psychosis between individuals with FASD and those without; behavioural disorders were 20% more likely in offenders diagnosed with FASD. In addition, results from this study seem consistent with the literature as there appears to be no impact of gender on an FASD diagnosis. Although males are more likely to have greater difficulties in attention tasks than females, they are subsequently diagnosed with ADD/ADHD, which is the most common psychiatric co-morbidity (Herman, Acosta, & Chang, 2008).

Although the majority of the offenders diagnosed with FASD admitted to intimidating or bullying others or just displayed disruptive behaviour at school, the differences were not significant. This finding is not surprising, considering many of these serious and violent offenders had negative childhood experiences comparable to those offenders diagnosed with FASD. However, individuals with FASD had a significantly more negative identity than those offenders not diagnosed. FASD offenders also had lower self-control based on risk-taking, temperament, and preference for physical rather than cognitive processes than those offenders not diagnosed.

With this combination of negative factors, it is not surprising that individuals affected by FASD have more negative events than non-FASD offenders, experience peer rejection, and resort to anger or physical aggression (Bohmann, 2000). This progression to physical violence seems to be consistent with the difficulties experienced in executive functioning by an individual affected by FASD (Kodituwakku et al., 2001). This evolution may ultimately result in a wider variety of criminal behaviours undertaken by the individuals diagnosed with FASD than offenders who did not meet the criteria.

Although this analysis provided some insight into characteristics common in individuals with FASD, many of these same traits were also present in non-FASD offenders. The serious and violent offender findings were also consistent with DeGusti, MacRae, Vallee, Caputo, and Homick (2009) who identified factors for youth at-risk which fall under five main domains: individual, family, peer, school, and community. Most chronic and persistent youth offenders were exposed to a number of complex

factors, similar to those examined here, including mental health problems, family violence, negative peer associations, and school difficulties. DeGusti et al. (2009) believe that the most effective strategies integrate interventions in all five domains. This study reinforces the integrated model proposed in this dissertation where multi-agencies are required, and initiatives to prevent criminality need to address the grass roots problems, in addition to difficulties associated with a diagnosis of FASD.

There were a number of limitations with this data that emerged from this exercise. The majority of the data were self-reported, although confirmation of information was obtained when possible. Extreme measures were taken to standardize the responses of the participants, but, numerous interviewers were used, which may have contributed to interviewer-related errors. Most importantly, because this population was a very specific one, that is, serious and violent incarcerated youth, results can not be generalized to other populations.

Implications of Secondary Disabilities

Without appropriate support and services, individuals affected by FASD are more likely to develop secondary disabilities; which evolve as a consequence of primary disabilities as the person matures (Morley, 2006). These secondary disabilities experienced by affected individuals can include “mental health problems, disruptive school experience, trouble with the law, confinement for mental health, drug and alcohol, or criminal issues, inappropriate sexual behaviour, alcohol and drug problems, problems with employment, dependent living and problems with parenting” (Morley, 2006, p. 13).

Due to the multitude of life trajectory challenges, FASD treatment strategies need to utilize an integrated service and policy approach. For instance, an “undiagnosed” FASD child may perform poorly in school as a result of learning difficulties, which can result in “marginalization during formative years, disruptive school experiences, as well as lifelong struggles related to low educational achievement” (Morley, 2006, p. 13).

The following is an example of an individual with FASD:

Eric demonstrated impulsive behaviours, had a poor understanding of cause and effect, had a variety of intellectual and physical difficulties such as problems with tying

his shoes and writing his name, exhibited poor money management skills, and had difficulty understanding social cues (Bohmann, 2000). However, Bohmann reported, the most devastating were the secondary outcomes related to FASD:

> Low self-esteem, anger and acting out, drug and alcohol abuse, suicide attempts, and a dark spiritual outlook. Even after he was treated with medication for depression, his opinion of himself remained dim. Once he told me he felt like an insect. (p. 131)

Research has indicated that the most significant risk factors associated with secondary disabilities in FAS/FAE are: IQ over 70 and exposure to sexual or physical violence. In British Columbia, individuals with lower IQs are likely to get more services and interventions, whereas those with an IQ over 70 would be considered independent. In addition, those individuals with exposure to sexual or physical violence would be at a greater risk for secondary disabilities, which occurs at a rate of 72% of individuals with FASD (Kellerman, 2002). As well, those individuals affected with FASD and who had previous exposure to violence are four times as likely to exhibit inappropriate sexual behaviour, which is one of the secondary disabilities (Kellerman, 2002).

On a promising note, a few protective factors have been identified. Early diagnosis is the prime protective indicator for all secondary disabilities. Only 11% of individuals with FASD were diagnosed by 6 years of age (Streissguth et al., 1996). Every effort must be made to obtain early diagnoses for children with FAS and FAE. Eligibility for services is another strong protective factor. Although these services are needed by most individuals with FASD, very few qualify.

Each province and territory sets its own age range for which child services are provided. Seven provinces and territories (Newfoundland and Labrador, Nova Scotia, New Brunswick, Ontario, Saskatchewan, the Northwest Territories, and Nunavut) provide protective services to children under age 16. The remaining provinces and territories provide child welfare services up to age 18, with the exception of BC, which

provides until the age of 19.[31] Once these individuals reach this predetermined age, the child welfare system officially considers them *independent adults* and the youth leaves care having "aged out" of child welfare care. Hence, in B.C., once the child has reached 20 years of age, the Child, Family and Community Services Act can no longer assist unless provisions have been established in an extension agreement with the Ministry of Children and Family Development. Recently, however, there has been significant progress addressing the major issues for youth transitioning to adulthood.[32]

As well as affected individuals losing services when they reach 20 years of age, those individuals who have an IQ of above 70 may not receive services as children. Statistics indicate that less than 8% of individuals affected by FASD have an IQ less than 70; therefore, these individuals are not considered mentally challenged. However, at the same time, these individuals can not live independently: According to existing B.C. policy, only people with an IQ of less than 70 are eligible for care, yet research clearly indicates that some individuals affected by FASD need support regardless of IQ score. A study in B.C. found that only 13% of adults with FASD were capable of living independently (Clark & Gibbard, 2003). This gap in policy needs to be addressed.

One further point: The B.C. Strategy states that one of the priorities is to enhance the accessibility and suitability of current programs and services in areas relevant to the comprehensive needs of affected children, youth, adults, and their families. However, services seem to be very limited for later-diagnosed teenagers and young adults.

Currently there is debate as to whether some mental health concerns, including depression, anxiety, and stress response may actually be primary rather than, as presently regarded, secondary effects of prenatal alcohol exposure (Weinberg, 2009). Regardless of whether these characteristics are primary or secondary, intervention needs to address the lifelong disability of FASD. With a better understanding of the

[31] Retrieved from www.cecw-cepb.ca - Transitions out-of-care: Youth with FASD in Manitoba, February, 9, 2012.

[32] British Columbia, Ministry of Children and Family Development, *Cross Ministry Youth Transition Planning Protocol for Youth with Special Needs*. (2012). Accessed at http://www.mcf.gov.bc.ca/spec_needs/adulthood.html.

characteristics and associated risk factors, there has been encouraging progress in the modifications, transitions, and accommodations for individuals with FASD (Malbin, 2008). With the recognition of the "life span nature of disability", most successful program models encompass harm reduction and the empowerment philosophy (Bennett & Woodward, 2010). As well, they acknowledge the requirement of continual funding of the individual; however, government funding sources are limited.

I have summarized the associated secondary disabilities as well as highlighted some of the inconsistencies with current government services. I will continue with a discussion of FASD characteristics that have predisposed individuals to criminality.

FASD Link to Criminality

A preliminary analysis of CanLII indicated that legal cases involving individuals affected by FASD are found at all three levels of courts within British Columbia (Table 4.4). The intent was not to provide an in-depth analysis, but to provide context and rationale for new initiatives for affected individuals.[33] For an excellent review of cases and current Canadian research see Vidovic (2012).

Table 4.4. Summary of Case Classifications and Attributes of Legal Cases Involving Individuals Affected by FASD

Case Classifications and Attributes	Provincial Courts of British Columbia (*n* = 44)	Court of British Columbia Appeals (*n* = 5)	Supreme Court of British Columbia (*n* = 16)
Canadian Criminal Code	32	5	9
Sentencing	21	5	9
Judge did not error		5	

[33] I do acknowledge the numerous limitations of using this data source, such as its not having a complete record of all cases, some relevant cases maybe not being represented as they were not stored in the database; and it not always being possible to get complete case histories (e.g., possible relevant information not present in appeal decisions or reports outlining reasons for sentence) (Vidovic, 2012).

Case Classifications and Attributes	Provincial Courts of British Columbia (*n* = 44)	Court of British Columbia Appeals (*n* = 5)	Supreme Court of British Columbia (*n* = 16)
Grant leave to appeal and dismiss Crown's appeal		2	
Infringement of Rights – Request for Assessment	4		
Order of certiorari			2
Accused possible FASD			2
Judicial Interim Release	1		
Dangerous Offender Designation	2		1
Long-term Offender Designation	1		1
Youth	5		1
Voir dire	3		1
Accused possible FASD	3		1
Offender			
Diagnosed FASD	11	3	1
Diagnosed ARND	1		
Possible FASD	15	2	3
Confirmed not FASD	2		1
Victim of Crime			
Diagnosed FASD	2		
Possible FASD	1		
Ministry of Child Family and Communities Act	12		7
Introduction of new evidence			1
Child possible FASD			1
Compensation for children			1
Child diagnosed with ARND			1
Multiple children diagnosed with ARND			1
Compensation for property damage			1
Accused possible FASD			1
Guardian's application for custody	3		1
Child diagnosed FASD	2		
Child possible FASD	1		1
Multiple children diagnosed/possible			1

Case Classifications and Attributes	Provincial Courts of British Columbia (*n* = 44)	Court of British Columbia Appeals (*n* = 5)	Supreme Court of British Columbia (*n* = 16)
FASD	2		1
Father diagnosed FASD	1		1
Supposal support	1		1
Director applied for Continuing Custody Order	9		3
Child diagnosed FASD	3		2
Child possible FASD	3		1
Multiple children diagnosed/possible FASD	3		2
Mother diagnosed FASD	2		
Mother possible FASD	5		

The majority of cases involved Canadian Criminal Code sentencing issues for males who were suspected of being affected by FASD but not confirmed. Almost all of the cases involved Aboriginal males who had multiple foster care placements and were described as having a "chaotic family life". In one case, an individual diagnosed with partial FASD had "approximately 62 foster care placements" (*R. v. J.E.R*, 2012) (Huitson, 2013). Another individual suspected of being affected by FASD and being considered for the dangerous offender designation was sexually abused from the age of 4 until about 12 by an adolescent male neighbour (*R. v. K.W.B*, 2013) (Table 4.4).

Most offenders also had extensive criminal records where most convictions were for violent or serious offences. For example, Mr. Makela, an individual diagnosed with partial FAS, was "being sentenced for his thirteenth through nineteenth armed robberies" (*R. v. Makela*, 2006). Similarly, Mr. Paquette, who was suspected of being affected by FASD, had a long criminal record including "possession of narcotics, possession of stolen property, break and enter, impaired driving, mischief, armed robbery, assault causing bodily harm, trafficking in a narcotic, obstructing a police officer, attempted fraud, fraud, uttering threats, and sexual interference. There are also convictions for violent behaviour including assault causing bodily harm, uttering threats and armed robbery". Mr. Synnuck was considered a "career criminal, having almost 60 convictions

on his record and having re-offended on 16 of 21 occasions he was released on probation" (*R. v. Synnuck*, 2005).

Any individual who appeared cognitively delayed and "slow to grasp" things was suspected of having some form of learning disability; and as awareness is growing for FASD, this is becoming one of the options that is considered, as in the following example: "She exhibits classic symptoms of the syndrome. She is low functioning. She is pleasant and really does try to please and that is one of the characteristics of FAE/FAS" (*Director v. R.M.*, 2004).

Although awareness of FASD and its subcategories is increasing, there are still some misconceptions as revealed, for example, in the following comments: "There are no physical signs of FAS, but he is to undergo further testing to see if he suffers from the emotional symptoms of FAS" (*L.A. v. Director*, 2002). As well, ARND has been referred to as *the new FAE*. On the other hand, there is some awareness that children with ARND have "normal looking faces, are not developmentally delayed physically, and who test in the average range for intelligence. However, they are not normal. They are cognitively damaged as well as psychologically damaged, when they are expected to perform above their level of social ability and punished for their failure when they can not" (*R. v. Harris*, 2002). In addition, "Dr. Constance agreed that Mr. Z. did not meet the criteria for FASD but that he had FAE" (*R. v. R.D.Z.*, 2012).

As well as misconceptions with terminology, there seem to be issues related to diagnoses and how they are determined. The Asante Centre was clear that they would only provide an FASD assessment of the accused if he could provide confirmation of the required prenatal alcohol involvement. In addition, in one case, the offender could not get "a medical assessment in the province of British Columbia because, for adults, that type of assessment has been privatized" (*R. v. Gray*, 2002). The judge stated "if cognitive and functional disabilities are indeed diagnosed and suspected to be attributable to FAS or ARND, depending on the comprehensiveness of the Forensic Psychiatric Services (FPS) assessment, the information and recommendations may be all that is necessary for the sentencing judge. It is only after the initial report by FPS has been received that a possible need for further information and assessment by a specialist, such as developmental paediatricians, will be necessary."

Many judges believe they are “being ordered by the Supreme Court to sentence” when they do not think they should be and are “being told by the British Columbia Court of Appeal” they should not sentence in the absence of a medical assessment. They therefore feel caught between two courts (*R. v. Creighton*, 2002). As well, many issues concerning diagnoses have emerged from court cases: “What duty to diagnose lies upon those responsible for maintaining our jails and prisons? What is the scope of the ethical duty to inform and to whom must such disclosure be made?” (*R. v. Creighton*, 2002).

Numerous cases referred to the offender as being “unable to retain in memory learning” and therefore concluding that ”such breaches are to be expected. He has limited cognitive capacity” and thus “it would be manifestly unfair to make him pay for his disability with his liberty” (*R. v. T.J.J.*, 2011). Some judges believed a diagnosis of FASD “should be treated as mitigating in sentence and provides some case authority” (*R. v. C.A.P.*, 2009).

Many cases referred to the “external brain” and stressed the need for a network of people around the affected individuals in order for them to function (*R. v. Harris*, 2002; *R. v. Gray*, 2002): “If they have not been diagnosed with FAS/ARND, they tend to lose such supports because they alienate people who do not understand their disability” (*R. v. Gray*, 2002). “They often require someone to act as an ‘external brain’ to provide them with assistance in dealing with information and situations that are difficult for them to comprehend” (*R. v. Ramalho*, 2004).

A number of cases demonstrated the vulnerability of individuals affected by FASD due to the fact that “FASD significantly reduces the capacity to realize the intentions of others and take steps to protect oneself from harm” (McGinn & McLaren, 2013, p. 372). Individuals affected by FASD have a lack of reserve with strangers and display trusting issues that can be easily detected and taken advantage of by criminal and sexual predators (McGinn & McLaren, 2013).

In *R. v. Kouznetsov* (2009), the offender was diagnosed with FASD and “was a person who was vulnerable to being involved by others in criminal activity”, as he was the “so-called getaway driver”. Mr. Williams was quoted as being an “extremely vulnerable person, who was lead by a friend and relative with a lengthy criminal record to do the dirty work”. In the case of Mr. Makela: “He joined a gang in prison for

protection. However he was kicked out of the gang as a result of drug use and otherwise being difficult to get along with, probably because of temper problems. So he has voluntarily spent significant amounts of his incarceration in a form of solitary or segregated confinement" (*R. v. Makela*, 2006).

A total of 19 cases involved the Ministry of Child, Family and Communities Act, whereas the majority of cases (*n* = 9) involved the Director's application for a Continuing Custody Order (CCO) (Table 4.4). In all five CCO cases, where at least one child was diagnosed with FASD, there were other children diagnosed or suspected of having FASD, as well. This finding is consistent with existing literature on families with multiple children having FASD (May, 2013).

In summary, this analysis provided evidence for a number of issues that have appeared in the literature. First, although there has been an increase in awareness of FASD (Table 4.5), there is still some misunderstanding in the terminology. Second, there also seems to be a lack of formal assessment of FASD during the court process. Third, there is still an over-representation of Aboriginals affected by FASD in the court system.[34] And, finally, more judges are taking FASD into account when sentencing, though this acknowledgement seems to be a personal decision due to the lack of standardization established in the court system.

Table 4.5. Summary of Cases Involving Individuals Affected by FASD by Year of Judgment.

Year of Judgment	Number of Cases
1994-1999	3
2000	4
2001	6
2002	13

[34] Almost 32% of the serious and violent offenders (*N* = 517) self-reported being Aboriginal and 54% of these youth were clinically diagnosed with FASD. Literature supports this over-representation of Aboriginals within the criminal justice system as well as those diagnosed with FASD (MacPherson & Chudley, 2007; Rojas & Gretton, 2007).

Year of Judgment	Number of Cases
2003	5
2004	5
2005	2
2006	4
2007	5
2008	3
2009	2
2010	1
2011	3
2012	8
2013	1

An increasing number of judges believe that the focus of sentencing for individuals affected by FASD should be the modification of their living or social situations rather than their behaviour (Vidovic, 2012). In keeping with this ideology, sentencing should provide structure, support, and treatment. In addition, the sentencing process would be more successful if surveillance and enforcement in the community were mandatory and standardized.

Impulsivity Linked to Criminality

Case histories have suggested that individuals with FASD may have *impulsivity* which is linked to aggression (Keinfeld, Morse, & Wescott, 2000). Impulsive aggression may be either verbal or physical "may be deliberate, non-premeditated aggressive acts…directed at another person, object, or the self and intended to cause harm" (Hollander & Stein, 2006, p. 8). Impulsive aggressive behaviours may cause significant harm in social, vocational, and family functioning (Hollander & Stein, 2006).

Many young children (later diagnosed with FASD) are initially regarded as having behavioural difficulties or "conduct disorders". *Conduct disorder* (CD) epitomizes the link between impulsivity and aggression. In early childhood or adolescence, symptoms of CD such as "aggressive actions that cause physical harm to others, damage to property,

deceitfulness, theft, and serious violations of rules" become apparent (Hollander & Stein, 2006, pp. 8-9). Other common characteristics of CD are risk-taking and impulsive behaviours. These behaviours may include drinking, smoking, drug use, and early onset of sexual behaviour. Even though aggressive features may be displayed by a person afflicted with CD, it takes an "impulsive nature to carry out the reckless actions associated with CD" (Hollander & Stein, 2006, p. 9). Whether or not a person acts out in an impulsive manner depends on the combination of aggression and impulsivity.

There are gender differences in how impulsivity is manifested. Aggressiveness in males is more commonly outwardly directed, whereas impulsive behaviours in females tend to be inwardly directed and non-aggressive (Hollander & Stein, 2006). Coccaro, Kavoussi, and Hauger (1998) believe these gender differences may be the result of genetic factors, hormonal differences such as testosterone levels, or differences in the regulation of serotonin and other peptides. However, some researchers believe gender differences may also derive from sociocultural factors (Hollander & Stein, 2006).

There has been significant research conducted on the biological basis of impulsivity which informs the conceptualization of Impulse-Control Disorder (ICD), and many of the identified biological bases for impulsivity are common in individuals affected by FASD. Several neurotransmitters are involved in the manifestation of impulsivity. For example, research on animals and humans indicates that a deficiency of central serotonin (5-hydroxytryptamine [5-HT]) is associated with greater impulsivity (Brown, Kent, & Bryant, 1989; Higley & Linnoila 1997; Linnoila, Virkkunen, Scheinin, et al. 1983). Also, populations with higher levels of impulsivity or sensation-seeking, such as bullfighters and bulimic patients, present lower levels of platelet monoamine oxidase (Carrasco, Diaz-Marsa, & Hollander, 2000; Carrasco, Saiz-Ruiz, & Diaz-Marsa, 1999; Hollander & Stein, 2006). Other transmitters that have been associated with modulation of impulsivity and aggression include γ-aminobutyric acid (GABA), norepinephrine, and dopamine (Oquendo & Mann, 2000). These same transmitters have also been linked with developmental and behavioural deficiencies due to prenatal alcohol exposure.

Most of the research in rats and humans that identified the neuroanatomic basis of impulsivity came from lesion studies (Hollander & Evers, 2001). In rat studies, impulsive choice on delayed reward tasks was associated with lesions in the nucleus accumbens, orbitofrontal cortex, and basolateral amygdale (Cardinal, 2001). Miller

(1992) found that frontal lobe lesions in humans were correlated with impulsive behaviour on cognitive risk-taking tasks. In particular, patients with lesions in the region of the ventromedial prefrontal cortex executed more impulsively in delayed reinforcement tasks (Bachara, Tranel, & Damasio, 2000). In addition, Berlin, Rolls, and Bryant (2004) discovered that patients with lesions of the orbitofrontal cortex were more impulsive than patients with lesions in the prefrontal cortex and normal control subjects on self-report and cognitive-behavioural measures. It appears that there may be a separate motivational salience that changes the function neuro-circuitry for each disorder (Hollander & Stein, 2006). Many of these regions identified as important for impulsivity have been associated with damaged areas due to prenatal alcohol exposure.

In summary, many of the structural and functional deficits found in individuals exposed to prenatal alcohol exposure lend themselves to susceptibility, school failure, and differential processing (Waage & Debolt, 2008). Each has been embedded in criminological theories that have predicted an association between learning disabilities and criminal behaviour. The next section will examine the rational choice argument: Are individuals affected by FASD able to "rationalize doing crime"?

Criminality is Based on Rational Choice

When one looks at crime, the concept of rational choice comes to mind to explain criminality; however, this notion is challenged when considering individuals affected by FASD. The main principle of the rational choice theory is that an offender has the ability to decide whether or not to commit a crime and to find the resources and the ability to commit the crime. Clarke and Cornish (2001) stress that the event decision-making process includes more than target selection alone. The process begins with what target should be selected, where one goes to obtain such a target, and, finally, the execution of the criminal activity (Clarke & Cornish, 2001).

One of the major criticisms of the rational choice theory is that it ignores the fact that each event is rooted in a previous event, so offenders affected by FASD do not have the "free will" to choose the course of action (Hirschi, 1986). Individuals with FASD have difficulty performing tasks that require planning, strategizing, executing, and modifying an act, as it progresses (Kodituwakku, 2009; Mattson et al., 1999). For

example, during the course of planning a murder, an offender will select a location that is familiar to minimize the likelihood of being caught. In the case of individuals affected by FASD, it can be argued that it is debatable whether the individual has the ability to make rational choices due to the deficiencies in executive functioning caused by prenatal ethanol exposure.

Research on mice and humans has indicated that the chemical activities in the brain required for decision-making can be affected by prenatal ethanol exposure (Bearer 2001; Queen et al., 2003; Savage et al., 2002). Therefore, the issue of poor discretionary decision-making ability in individuals affected by FASD can be raised. The rationale: If a person has a limited ability to distinguish between right and wrong, compounded by chemically-based impulsive decision-making, this combination could be a logical model for explaining impulsive decision-making. (See Table 4.6). For example, I see the candy…I take the candy. Between seeing and taking there are impulse controls and chemical activities that stop the body (fear and paralysis) which enables the brain to kick in a response such as, I might get caught. However if there is no chemical reaction to cause the paralysis, then there is no time to stop and reflect. Still, as not all individuals affected by FASD get involved in crime, it can be argued that it depends on the diminished capabilities of the affected individual and whether there was enough chemical reaction (or social control?) to stop the taking of candy and enough insight to say, I can get caught.

From the legal perspective, the commission of a crime appears to be a rational choice process. And currently the criminal justice model does not adequately address the disposition of cases involving the FASD offender because the focus is on the event rather than the individual. Therefore, for an individual diagnosed with FASD, one needs to look at the biological mechanisms that drive the offender.

Table 4.6. Explanation of Steps of Rational Choice for Different "Criminals".

Steps in Rational Choice Model	Rational Choice Non-Criminal	FASD Decision	Rational Choice Criminal	Impulsive Non-FASD
Purpose	Can do	Impaired	Can't do. Choose not to stop	Can't stop
Risk/Benefit	Can evaluate	Impaired will take immediate benefit and will	Weighs outcome choices. Can't evaluate	Can't stop

Steps in Rational Choice Model	Rational Choice Non-Criminal	FASD Decision	Rational Choice Criminal	Impulsive Non-FASD
		not consider risk		
Decision-making varies with the nature of the crime.	Can adapt	Poor decision-making due to low executive functioning	Does it regardless of nature	Impulsive Will not consider nature of crime
Involvement decisions: The initiation stage of commencing, the continuation and finally, cessation of the criminal behaviour.	Can accomplish	Will be impulsive, may not even recognize or understand the stages	Choose to commence the crime and continue	Will do without forethought
Event decisions: Selecting particular targets and considering ways to avoid detection or apprehension	Can be selective	May not have the ability to select targets Poor social cues	Selects minimum risk targets	May select easiest target Will not consider apprehension
Recognizing that individual's decision to initially involve oneself, continue or stop criminal activity will vary as a function of his background characteristics, current life circumstances and the situational variables at the time in question	Can recognize	Would not be able to decide Poor memory, would not be able to use past experience Low executive functioning	Will have the ability to stop or adapt due to situation	Goes for immediate reward Will not be able to adapt or stop

Table 4.6 represents the high-level review of the executive functioning decision-making process of the rational choice theory. FASD literature suggests that prenatal ethanol exposure produces deficits in activity dependent potentiation in glutamate release via a reduction in a PLC-β1→PKCβII/ϵ→GAP-43 phosphorylation signaling cascade. As well, alcohol intake affects the PKC-dependent phosphorylation of GAP-43 which may be a critical step in synaptic plasticity mechanisms underlying learning (Savage et al., 2002). Memory impairments of FASD affected individuals are linked to neurophysiological alterations that diminish activity-dependent enhancement of

hippocampal synaptic neurotransmission, specifically the NMDA and GABAA receptor numbers and modulation (Abdollah & Brien, 1995; Bailey et al., 1999, 2001; Costa et al., 2000; Savage et al., 2002; Sutherland et al., 1997). These are just a few examples of biological mechanisms which contribute to low executive functioning that have been affected by alcohol intake and, hence, criminality.

Besides the criminal aspect, typical crime prevention techniques would not be successful for an individual affected by FASD. For example, Situational Crime Prevention (SCP) focuses on eliminating or minimizing the opportunities available for crime, by modifying the environment. SCP encompasses "opportunity reducing measures that (1) are directed at highly specific forms of crime, (2) involve the management, design or manipulation of the immediate environment in a systematic and permanent way as possible, (3) make crime more difficult and risky, or less rewarding and excusable" (Sexton, 2002, p. 624). However within the SCP model, there are a number of assumptions such as: (1) offenders process environmental cues to determine target vulnerability (physical or psychological), (2) targets can be designed to send cues to offender which indicate ability to resist attack(s), and (3) occupants decide to defend their space which sends cues to offenders. As mentioned earlier, individuals with FASD have the inability, in most cases, to process or interpret environmental cues.

This inability to react appropriately to environmental cues influences the most controversial issue with those individuals affected by FASD: The sentencing. A crime is committed that cannot be excused, but how "fair" is the sentencing of an individual affected by FASD? For a specific crime, one can (1) use rational choice to explain the decision-making process, (2) use biology to explain how decisions are made, (3) show how individuals with FASD have low executive functioning and hence, a "damaged" decision-making process, and (4) show implications of inappropriate approaches, due to the variety of FASD "symptoms", on the criminal justice system as well as policy.

Typically individuals have rational choice. However for individuals affected by FASD, another factor seems to be involved in decision-making, environmental cues that trigger a biological reaction such as fight or flight. Therefore some individuals with FASD do not have the biological capability to stop themselves, once they have started to engage in an act. This notion invites revisiting the fundamentals of a crime and the goal

of justice. Because there is no standardization in sentencing procedures, great variation in sentencing options is apparent (Huitson, 2013).

In recent times, great strides have been made in educating personnel in the criminal justice system, such as police and lawyers, to recognize the disabilities associated with FASD and implement a more appropriate, multidisciplinary approach (Connor, Brown & Adler, 2009). People within the criminal justice system as well as caregivers for individuals affected by FASD, have been the focus of many program initiatives which aim to address these deficiencies (Table 4.7).

Table 4.7. Exemplar[35] Program Initiatives to Address Criminal Justice System Concerns.

Program Initiative	Description	Source
Education and awareness of FASD for justice professionals	Public Health Agency of Canada (PHAC)'s FASD Initiative is to develop tools and resources for use at the community level or for training to improve the capacity of communities to meet the needs of those affected. Equally important is improving the understanding among professionals of how FASD affects individuals and families. As such, the FASD unit within PHAC has been collaborating with the Department of Justice regarding FASD as it relates to justice issues.	Reeve, Fox, & Bedard, 2009, p. 171
Lethbridge Community Justice Program	Purpose to influence change in the system through mentorship, education and training Main objectives: (1) to influence case management for youth affected by FASD, (2) to divert youth affected by FASD from the system, where appropriate; and (3) to make recommendations to court.	Waage & Debolt, 2008
Manitoba Youth Justice Project	Prevention of crime by addressing circumstances of young person's offending behaviour, rehabilitation of young person who offends, and reintegration into society, ensuring the young person has meaningful consequences for his/her offence. Goals: to assess youth involved with the JS who may have FASD, to provide recommendations to the courts for appropriate dispositions consistent with the sentencing principles of the YCJA, to build the capacity	Singal, Brown & Chudley, 2013; Longstaffe, Harvie, & Brown, 2008, p. 176

[35] Exemplar, in this case, means an ideal model worthy of replicating. This may be deemed exemplar by experts and not necessarily by positive program evaluation.

Program Initiative	Description	Source
	within the family and community while enhancing government and non-government FASD supports and services, and to implement meaningful multidisciplinary intervention and re-integration plans with supports for youth affected by FASD and their families.	
Thompson Rivers University FASD program	Education and awareness of FASD is critical issue for providing the community infrastructure needed to effectively support individuals diagnosed with FASD. Provide a post-certificate program in FASD and Addictions and the Social Service certificate with a specialty in FASD and Addictions. Williams Lake campus continues to offer an introductory course for all its Human Service Programs as well as to the general student population. Students learn skills in effective teaching, dealing with behaviour issues, how to advocate effectively for high risk clients, community development, and about a number of different systems in their respective communities (legal, educational, health, etc.) - the hope is that graduates' experiences will enrich other communities' attempts to develop comprehensive training in FASD.	www.tru.ca/hse/programs/sped/courses.html
Lethbridge College Fetal Alcohol Spectrum Disorder (FASD) Education Program	One-year certificate that can transfer into the Disability and Community Rehabilitation Diploma. Coursework includes topics on prevention, intervention strategies, behaviour associated with FASD, functional assessment, family support, cultural diversity and case management.	Lethbridgecollege.ca/FASD
College of New Caledonia Advanced Diploma in FASD	Professional program to provide skills to: -Improve services and education for individuals with FASD. -Impact policy development. -Understand the complex challenges facing individuals, families, and communities. -Design and implement effective prevention and support strategies. -Understand the complex physical and social impacts of FASD.	www.cnc.bc.ca/lakesdistrict
College of New Caledonia Children, Family and Community Programs	Family Centred Program offers Healthy Start for Mommy and Me Support and Advocacy. Ashurst Children's Centre provides full service daycare more tailored for children with FASD and other disabilities. Southside Family Centred Program A Community FASD Prevention Program Healthier Babies - Brighter Futures (HBBF) Early Intervention Therapy Services	www.cnc.bc.ca/lakesdistrict

Program Initiative	Description	Source
	Kids' Edge (FASD Prevention and Intervention) Complex Developmental and Behavioural Conditions (CDBC) Assessment and Support Services Drop In Program.	
Corrections to Community (C2C)	Fort Saskatchewan Correctional Centre and University of Alberta's Occupational Therapy Department and Bissell Centre --includes screening and assessment, transition support worker, group psychotherapy, traditional sharing circles, psycho-educational programming, art therapy, mind, body, spirit.	Brintnell, Martell, & Smallacombe, 2009
Mind, Body, Spirit Experience in Reestablishing a Cultural Identity in Female Adult Indigenous Offenders with FASD	The first activity-based demonstration program designed for a provincial correctional site focused on identity exploration and development (person), Native cultural context (environment) and traditional activity exploration (occupation). Drawing on Native traditions and ceremonies, the program was perceived as the first step in enhancing personal skills for transitioning from jail to the community and for increasing behaviours which stress the social dimension of community life. The ultimate expected outcome was to increase community tenure and decrease re-offending behaviour - both males and female.--- Second program for woman only - same principles. A traditional Native perspective is taken on the role and behaviours of women in preparing them for community integration - this is more intensive and shorter experience - will link some of the participants to a community agency which offers a specific program to support their seamless transition to the community. A proposed designated support worker is a key element in the transitional program design. An analysis of the known performance barriers through component focused (affective, cognitive & physical) activities provides participants with a greater understanding of the power of culturally based occupations (activities) as intervention tools.	Brintnell et al., 2009, p. 210
Asante Centre for FASD	Youth Justice Program. Youth Probation Officers' Guide to FASD Screening and Referral.	Conroy, Singal, Bloom, & Burns, 2013; www.asantecentre.org

I have presented some current initiatives addressing criminal justice issues, which acknowledge the particular needs of individuals affected by FASD. There is a growing recognition of the secondary disabilities of FASD and the associated link to criminality, but this development is still in its infancy and specific (governmental) sanctions need to be established to "manage" these individuals. I will now continue with

exemplar initiatives addressing the “management” of affected individuals, as well as of caregivers, families, and community support programs.

Exemplar Policy Initiatives

Recent research has focused on “filling in” the gaps of knowledge. Momentous advancements have been made in three of the main areas: management of the individual affected by FASD, support for affected individuals as well as caregivers or educators, and, lastly, initiatives involving entire communities. I will begin with a discussion on individual management.

To understand appropriate management of affected individuals, studies have focused on the “barriers to accessing services” for high risk women and other individuals affected by FASD. A significant number of barriers to health and support services have been identified, including a general lack of locally available programs and transportation. In addition, the administrative process required to participate, program structure and content, and the choice of physical environment often do not take into account the “challenges” associated with being an individual affected by FASD (see Malbin, 2008; Rutman, 2011). Many of the new initiatives attempt to provide accommodations to reduce the challenges with obtaining services. Table 4.8 highlights some of the more promising initiatives focused on management of individuals affected by FASD.

Table 4.8. Most Promising Initiatives: Management of the Affected Individual.

Program Initiative	Description	Source
Asante Centre for FASD	Besides diagnostic and assessment services, Asante Centre provides outreach services, coordinated care plans, support services before, during and after diagnosis, consultation services, speech and language services, educational activities, and networking opportunities.	www.asantecentre.org
Bridge Program	Is a unique service delivery model that provides individualized, integrative, and coordinated support to youth with FASD, ages 17-23 years, living in the Vancouver Coastal and Fraser Region of British Columbia. PLEA Community Services Society of B.C. The Bridge Program; a promising practice to address the gap in support and services for youth with FASD making the transition to adulthood.	Hartley & Dewar, 2010; www.plea.ca

Program Initiative	Description	Source
Genesis	Day Program - Offering Vancouver Youth Opportunity. To provide young people (16-18 years) with an option for: academic upgrading to Grade 10 completion, vocational and job readiness training Program components: students attend a minimum of 3 hours each day, self-paced with teacher and youth worker support, and opportunity for completion of all Grade 10 courses required for graduation, yardworks work experience, field trips, school meal program, and additional support services available through PLEA.	www.westcoastgenesis society.ca
MILE program	Treatment programs for children with FASD. Support, educate, and empower caregivers. Achieve learning readiness (Behaviour/arousal regulation). Improve mathematical achievement by compensating for core deficits.	Coles, 2011b
GoFar FAS: Affective and Cognitive Training	Treatment programs for children with FASD. Development of a novel and effective intervention method for children with neurodevelopmental deficits associated with prenatal alcohol exposure by targeting the affective and cognitive control deficits (ACCD) common in this population using a combination of "serious" computer games and experimental learning.	Coles, 2011b
Paws on Purpose - Animal Assisted Therapy	A goal-directed intervention. It has been suggested that one strength of clients with FASD is that they often work well with animals, and working with animals gives an opportunity for professionals to apply principles of how to work with clients with FASD in a positive environment. Different animals provide different benefits - cats - can teach clients about boundaries, can be used to comfort clients, work on fine motor skills through petting and brushing and are not as intimidating to some clients as dogs; dogs - most popular, unconditional love, no shame, smart, friendly, cuddly, versatile; and can be used passively such as petting the dog, or actively such as walking the dog or having it do tricks. Horses - motivators to participate, excellent mirrors for client behaviour; and can be used for both physical and psychological/emotional therapy. What are the benefits - increase motivation, reduce depression, reduce anxiety, increase communication, facilitate bonding, help clients trust the therapist, provide insight into behaviours, catalyst for conversations, incentive for therapy	Anderson, 2009; Lieber, 2003 www.ChimoProject.ca

Program Initiative	Description	Source
	work, increase activity level, provide comfort, and help motor skills. Big 5 improvements - decrease anxiety, increase participation, increase motivation in session, increase in social interactions, and decrease depression.	
Behavioural assistance dogs for individuals with FASD	Creating unconditional companionship through intervention and support. -improved communication and social skills, -the dog's presence provides a positive distraction, calming and a unique sense of security to the recipient and their family. Anecdotal evidence suggests that abstract and concrete thinking advance, focus improves, and the length of attention span increases. Emotional outbursts occur less often and with less intensity. The ultimate role of the service dog is affording the individual more independence and autonomy, improved self-esteem results from the unconditional companionship and access to participation in the greater community-- this assistance includes protection (keeping child from running into street or wandering off) and empowerment.	Winokur, 2013; Winokur & Kulp, 2009.
FASD Therapy Project	-Is a specialized form of supportive therapy that involves creative action and creative thinking. <u>Youth art therapy</u> -It is not bound to talk therapy and is not limited by language and therefore can be more effective than talk therapy for youth who have visual spatial processing strengths. -it provides youth with creative/visual means to express themselves, learn and reinforce the learning of new things and interact with others. -it is less threatening and a more manageable and more comfortable approach for them than talk therapy. <u>Parent therapy group</u> -the tool places youth in the role of an expert in managing FASD by teaching disability awareness and coping strategies in the areas of: (1) social/relational skills; (2) learning in school and at home; (3) healthy family dynamics; (4) self-regulation; and (5) strengths and abilities. Activity goals: to promote creative thinking; develop more skills for creative communication with their child; and activities are useable at home with child.	Dick & Schwab, 2009, p. 262
Sam's Bear	Children's storybook -highlights in a child-friendly manner, some of the major modifiable factors that influence brain development both prenatally and in	Dedam-Montour, 2011, p. 426

Program Initiative	Description	Source
	the early years of childhood and how brain development (or lack thereof) can affect a person throughout life. Targets 5 - 8 yr olds. Sam's Bear is told from the perspective of the child's bear in the home - the story progress from the point of waking up, dressing, and preparing for school, and then after school, where Sam has his share of difficulties due to the "big boo-boo" in his brain. It explains how his brain was hurt before he was even born --goes into detail. A guide is provided for family, friends, educators, etc.	
Approaches for Discipline for Youth with FASD	Relationship Based Strengths Approach (RBSA) to helping; being proactive - predicting and preventing meltdowns; managing crisis situations, and following a "meltdown".	de Groot & Opie, 2009, p. 258
Dietary Interventions	Choline supplements given prenatally and postnatally reduced deficits in working memory, reduced over-activity, impacted spatial reversal learning deficits, and reduced trace eyeblink deficits.	Coles, 2011b, p. 347; Pei & Walls, 2010; Ryan, Williams, & Thomas, 2008
Dietary Interventions	Antioxidants, molecules that possess the ability to stabilize free oxygen radicals, are seen as favourable and a reasonable intervention based on the fact that oxidative stress from alcohol-induced cellular damage is a major mechanism in FASD.	Cohen-Kerem & Koren, 2003
Dietary Interventions	Vitamin E and Vitamin B-carotene were found to offer neuroprotection to hippocampal neurons despite ischaemia and hypoglycaemia.	Mela & Obayan, 2007, p. 329
Dietary Interventions	Vitamen A metabolism and ethanol detoxification results in a "starvation" for retinoic acid during embryogenesis and can be manipulated reducing the teratogenic effects of ethanol. RALDH2 is one of the earliest activities affected by ethanol competition. Variants of the RALDH2 gene might be responsible in part of the genetic predisposition to FASD.	Fainsod & Hinks, 2013, p.294
Optimal diets	Healthy diets including fresh fruits and vegetables, reduce sugar, eliminate food coloring and preservatives, avoid gluten and milk, and avoid salicylates (Feingold diet).	Wozniak et al., 2009
Melatonin replacement therapy	Sleep disorders of children with FASD are similar to sleep difficulties in children with other neurodevelopmental disabilities. The sleep difficulties are related to severity of cognitive loss and associated brain damage rather than to the specific diagnosis. Most of these sleep disturbances	Jan, 2011, p. 315

Program Initiative	Description	Source
	are delayed sleep onset, frequent awakenings during the night for minutes or hours and early morning awakenings. They are generally diagnosed as circadian rhythm sleep disorders which are defined as dissociations between the sleep-wake behaviours and the environment. Melatonin replacement therapy usually corrected these sleep disturbances because the pineal melatonin secretion in these children is reduced or inappropriately timed. Inadequate sleep results in behavioural and neurocognitive dysregulation and impaired health.	
Dialectical Behaviour Therapy	Well evaluated therapy protocol which has demonstrated good outcomes with individuals with repetitive use of self-injury and suicidal behaviours.	Opie, 2009, p. 343
Enriched environments	Enriched environments have resulted in advances in motor training and exercise in animal models.	Christie et al., 2005; Klintsova, Matthews, Goodlett, Napper, & Greenough, 1997; Klintsova et al., 2002
Occupational therapy	Assessment of sensory motor domain in FASD - movement assessment battery for children (MAB-C), the Beery Developmental Test of Visual-Motor Integration (VMI), and the Short Sensory Profile.	Fjeldsted, 2009, p. 359
FAST Club	After school motor-skills program for children with FASD. The goal is to help children tap into their inner strengths with regards to their motor and gaming skills as well to investigate whether these activities cross over into other areas.	www.ufv/kpe/FASTclub.htm

A number of common themes have emerged from these exemplar initiatives. Some of these promising accommodations include individual case management with reminder phone calls and check-ins, one-to-one support, more intensive support if required, knowledgeable staff familiar with the “disabilities” of FASD, and more relaxing program environments such as outreach approaches (Rutman, 2011). Programs that are successful, such as FAST club, tend to focus on the individual’s strengths, rather than the negatives. Furthermore, dietary interventions and enriched environments have addressed identified risk factors and provided some positive management strategies.

Modern initiatives continue to incorporate more of a “support circle” and holistic approach, acknowledging that FASD is not an easy, “fixable”, individual problem. Great strides have been made to educate and provide services for anyone who is involved with high risk women or individuals affected by FASD (Table 4.9).

Table 4.9. Most Promising Initiatives: Support for the Individuals, Caregiver, or Educator.

Program Initiative	Description	Source
Parenting Enhancement Program	Existing services for parents with intellectual disability.	Tao, Temple, Shewfelt, & Clifford, 2010
Personal Supports Initiative	Will provide new support to some adults with FASD, money is from BC Government to Community Living BC (CLBC), eligibility is for confirmed diagnosis of a FASD and adaptive function 3 standard deviations or less; IQ is above the cut off for regular CLBC services.	Bryne, 2010
Youth detox and supported recovery Plea addiction services	Community-based service for young people 16 and under who need a break from using alcohol and drugs. PLEA addiction services--The program uses a unique Family Care Home model - which means living with a family trained in youth addictions - so the young person remains connected to the community. Provide individualized service based on their strengths and needs, to help them overcome challenges and meet their goals Youth Detox, Residential Addiction Treatment (Daughters and Sisters, Waypoint), and Supported Recovery. Supported recovery is a 28-day residential program for youth 21 and under - provides safe, supportive place while you stabilize and work on your addiction treatment plan.	Youthinbc com/resources /plea/
Support for Caregivers	Caregivers of youth with FASD experience higher levels of burden as a result of secondary disabilities subsequent to the primary disability of neurocognitive dysfunction.	Roger, Plesuck, & Schultz, 2013; Pereira, 2010
Supportive Optimistic Advocacy Restorative (SOAR) Mentor Program	Offered through the Inter-Tribal Health Authority (Vancouver Island First Nations).	Rutman, 2011
Whitecrow Village's Addictions Recovery Support Group for Adults with FASD	Offered through Whitecrow Village (based on Vancouver Island).	Rutman, 2011
Mentor-advocate project FASD Support Network of Saskatchewan	People with FASD are often unable to create circles of support independently - leading to isolation and exclusion - this can increase the risk of the occurrence of a mental illness as well as increase the severity of symptoms and decrease the likelihood of accessing appropriate services --reducing isolation and exclusion can result in reducing severity of symptoms and occurrences of mental health issues leading to healthier and safer lives. Individualizing mentoring - based on a sound understanding of FASD and knowledge of the unique characteristics of each individual, has led to improved mental health by fostering a	Palibroda & Wood, 2008, p. 97

Program Initiative	Description	Source
	genuine sense of belonging - the mentor has acted as an external brain and has been an "anchor" for each individual - positive mental health has been promoted by using concrete approaches to address and manage the complexities of daily life. The relationship with a mentor has been made to develop a circle of support around each person.	
POPFASD - Provincial Outreach Program for FASD	Mandate to increase the teacher's capacity to meet the educational needs of students with FASD. Provides access to resources via the website, delivers online eLearning video modules, facilities and presents workshops, support school districts to build capacity for successfully meeting the educational needs of learners with FASD by working with District Partners, liaises with other ministries, synthesizes and shares current FASD research, provides consultation and support to teachers, consults and liaises with the experts in the field of FASD and facilitates information sharing.	Hughes & Wakabayashi 2008, p. 10
Family-focused, multisystemic counseling, support, and advocacy for families raising children and youth with FASD	Family identifies their needs, desires. Goals are decided together with the family. Services start with what is most important to the family Service providers join with the family to work together regarding identifies goals.	Opie, 2007, p. 105
Options For Independence Non-profit society funded by the Yukon Government	Offering long-term supportive housing to adults affected by FASD who are at high risk of homelessness.	Amerongen & Seier, 2007, p. 207
Life's Journey Inc.	Manitoba FAS Community Mobilization Project The model: Practice-based model that utilizes a best-practices approach based on the longitudinal finding of Streissguth (1997), others prominent in the field, and anecdotal experience gained through the FASD Life's Journey Program; Case management (advocacy) mentorship model; framed by a harm reduction and empowerment philosophy; recognizing the lifespan nature of the disability - won't accept temporary funding for an individual. Assist youth with FASD to transition to adulthood; assist youth and adults with FASD to function more independently in the community; and increase the functioning and quality of life of youth and adults who have FASD.	Bennett, Wyllie, & Bjorklund, 2007, p. 231; Bennett & Kydd, 2009
Healthy Generations Family Support Program	Provides services to families raising children with FASD to minimize its impact on children and their families. We believe with understanding and appropriate supports, individuals can live successful lives. Services include: support for the parents and the child; advocacy for the parents and the child; parent support group; telephone support calls, home visits, training and education for	Lauer & Kay, 2009

Program Initiative	Description	Source
	the family and the child's support system; use of resources, books, and videos.	
Adapting the roots of empathy program for students with FASD	Roots of empathy is an evidence-based classroom program that has shown dramatic effect in reducing levels of aggression among school children by raising social/emotional competence and increasing empathy. To foster the development of empathy, to develop emotional literacy, to reduce levels of bullying, aggression and violence, and promote children's pro-social behaviours; to increase knowledge of human development, learning and infant safety; and to prepare students for responsible citizenship and responsive parenting. Class visits, instructor visits, and curriculum manuals - pre-planning visit, family visit, post family visit. ROE is recognized as an effective social and emotional competence program - the ability to identify and regulate their own emotions (recognize, understand, cope with, express); key to successful relationships and conflict resolution and empathy is a component of social and emotional competence.	Kathy, Schwab, & Letchford, 2009, p. 242
Practical School-based approach in northern native communities	"FASD in Lab Mice" Dramatic effect in increasing Alaska Native students' understanding of the lifelong neurological and physical damage caused by drinking during pregnancy and, more importantly, led them to engage in active prevention efforts in their own and other Native communities. FASD in Lab Mice prevention program, using actual experiments conducted by the students themselves, provides compelling evidence regarding the pervasive effects of alcohol on the developing fetus. The program received strong support from Native communities and incorporated community values of reverence for animal life with the use of animals for practical human purposes.	Jacquier, Gilliam, & Kleinfeld, 2009, p. 261
"Cultivating creative children"	To provide respite, support and information for parents/caregivers in a caring, sensitive and culturally diverse setting. Children with cognitive learning disabilities were given the opportunity to acquire new skills while enjoying a safe, fun filled environment. Additional program objectives included strengthening community support and awareness for individuals with cognitive disabilities and enhancing knowledge and prevention of FASD.	Yakowec & Edin, 2009, p. 368
Partners for Success (PFS) Family-based therapy	1) In-Home Family Therapy 2) Online Caregiver Support Group 3) Mentorship: Young Adult	Tenkku, 2011, p. 370
Cognitive Behavioural Therapy (CBT)	Decreases parental stress, increases parent empowerment and parent coping skills and supports relearning.	Tenkku, 2011, p. 371
Solution-focused Therapy (SFT)	Addresses non-FASD related mental health issues within family unit through an family-centered, family-lead therapeutic	Tenkku, 2011, p. 371

Program Initiative	Description	Source
	approach; supports brainstorming and adaptations for in addressing changes related to FASD.	
CAP - Curriculum for Addiction Professionals	To educate addiction professionals on: (1) the science, historical perspective and identification of FASD, (2) the behaviours and characteristics through the lifespan, (3) prevention of FASD with high risk women, and (4) counseling techniques for clients, adolescents and adults with FASD and possible FASD, and their children. Level One - knowledge-based model Level Two - skills based model	Mitchell, 2007, p. 128
Assimilation, Integration, Marginalization and Segregation (AIMS) Interview and Functional Assessment were used to assess community integration and level of support needed	Results indicated that most of the adults with FASD were integrated (i.e., Disability-related needs were identified and supported) in the following domains: medical, dental and housing; however, a large percentage were marginalized in other domains. Living with a caregiver had the greatest positive impact on integration while a history of incarceration or confinement had a negative impact. The adults with FASD who have more complex needs were less likely to be perceived as integrated.	Clark, Minnes, Lutke, & Ouellette Kuntz, 2007

In addition, there has been great advancement in the implementation of initiatives within communities. FASD interventions seem to incorporate partnerships and networks, with the main focus on addressing the gaps in knowledge and the barricades to existing practice and policy (Table 4.10).

Table 4.10. Government Inspires "Most Promising" Community-Based Policy Initiatives.

Program Initiative	Description	Source
Telehealth for Diagnosis and Follow-up of Individuals with FASD	Funding from Manitoba government to the Clinic for Alcohol and Drug Exposed Children (CADEC) to incorporate Telehealth in the diagnosis and follow-up in referrals of children suspected to have FASD. Telehealth uses telecommunication technology which enables residents of rural and northern Manitoba to receive comprehensive health care services over a distance link. Manitoba's Telehealth service has allowed children and families to receive multidisciplinary assessments for FASD from their home community and has been instrumental in providing consultation to communities in order to build capacity in assessment, diagnosis, education and follow-up.	Edwards & Hanlon-Dearman, 2013; Longstaffe, 2010
Telehealth consultation model for FASD assessment and follow up by community-based	Many smaller regions have the need, but not the capacity, to provide FASD assessment/diagnostic services. -Allowed clinical staff in ECH (East Central Health) the	Andrew & Schuller, 2007, p. 90

Program Initiative	Description	Source
teams	opportunity to be mentored by the GRH (Glenrose Rehabilitation Hospital) team while establishing a clinical service in their region.	
FASD Online Training tool for physicians and health and social service professionals	Goal to reach a large number of health professionals and social service providers in order to increase knowledge about FASD issues and alcohol use in pregnancy. This tool has been developed in order to help health professionals and social service providers feel more at ease in addressing this issue, opening discussions, giving accurate information, and suggesting intervention methods is needed.	Desourdy & Turmaine, 2009, p. 370
Virtual collaboration	Linking research practices and policy.	Poole, 2007b
Calgary Fetal Alcohol Network: Building community capacity	CFAN Initiatives: FASD MAPS - mentorship and advocacy partnership and support, circle of friends, support groups, directory and resource fair, FASD Day, conferences, central number.	Deib, Evans, & Palashniuk, 2009, p. 121
	B.C. model of service delivery has components of: British Key Worker/Care coordination model; Diane Malbin's Oregon FASCETS project model (empowerment and neurobehavioural); Victoria community circle's family support research model (contact at diagnosis). BC Key Worker and Parent Support Programs - the goal is to: (1) maintain and enhance the stability of families of children and youth with FASD and similar neurodevelopmental conditions; (2) increase the knowledge of parents and professionals about the neurological nature of developmental-behavioural conditions such as FASD; (3) ensure that families of children with FASD and similar neurodevelopmental conditions have an ongoing network of support. -assists families in accessing support, health and education services and is involved in development of local support services; provides emotional and practical support to families; and strives to empower the family to become their own best advocates for their child.	Hume, Luettgen, Rutman, & Hubberstey, 2009, p. 269
Alberta Vision	Comprehensive and coordinated provincial response to FASD across the lifespan and continuum of services. It is respectful of individual, family and community diversity. Philosophy, sensitive to developmental level, strength-based approach, community solutions, promote specialized approaches to assessment, intervention, and support. It is an issue for: Health, Education, Justice - involving Children and Youth Services, Seniors and Community Supports and Public Assistance Programs Includes Outreach Program, Life Coach Program, Youth Criminal Justice Act Project Officer.	Elliot & Lorenz, 2010
Canada Northwest FASD	A Prevention Network Action Team was established to	Burnside,

Program Initiative	Description	Source
Partnership	provide an opportunity for the stakeholders of programs in northwestern Canada (mentors, supervisors, women participants, and other community members) to share their experiences, with a view to developing a more complete picture of the role of mentoring in the lives of these women.	McDermott, Gough, Tanchak, & Reinink, 2011, p. 423

The B.C. Government has acknowledged that the solutions to FASD "lie in the networks of community supports" (BC Government, 2003, p. i). Therefore, a number of networks have been established as government initiatives. For example, Alberta Vision, as well as the Northwest Central Alberta FASD Network have united individuals and organizations all with a common goal, for more research and appropriate practical and policy initiatives. This type of network provides a forum to interact, encouraging research, increasing knowledge exchange, and providing relevant services.[36] More specifically, research networks are emerging, bringing together researchers from various health disciplines and incorporating innovative methods such as virtual collaboration (Poole, 2007b; Poole, Salmon, Hache, Rutman, & Gammon, 2011).

So how is it possible that with all these great advances, specialized and integrated holistic initiatives and innovative methods of collaboration; there is still FASD? There are still high risk women and individuals with FASD without support and inaccessible services. Why have we failed? To conclude this chapter I will highlight the disjuncture in a FASD policy, "Fetal Alcohol Spectrum Disorder: A Strategic Plan for British Columbia" (2003).

Rhetoric or Reality

The government's 2003 strategic plan, subsequently referred to as the BC Strategy, reflects collaborative work by stakeholders including affected parents, individuals affected by alcohol exposure, advocates, teachers, health and other service

[36] Government of Alberta. (2008). FASD 10-year Strategic Plan. Retrieved July 17, 2012 from http://www.fasd-cmc.alberta.ca/uploads/1004/fasd10yrplanfinal86321.pdf.

providers, as well as governments. The intent of the BC Strategy is "to provide policy makers, community groups, and researchers a map of the multi-layered and multifaceted work involved in the prevention and intervention and support for FASD" (BC Government, 2003, p. 5). More specifically, the goal of the document was to generate discussion with community partners to consolidate action priorities by all sectors for 2003-2006.[37] In addition, the success of the vision is dependent on its coordination and integration across all sectors (BC Government, 2003).

The principles and values highlighted in the BC Strategy include comprehensiveness, collaboration, and evidence-based initiatives. The majority of the strategic plan is dedicated to the options for FASD strategic initiatives that focus on different sectors including communities, service providers, researchers, and policy makers (BC Government, 2003). These initiatives include the following:

- Community development, health promotion, and public awareness strategies to raise awareness of FASD as a life-long disability and the risks associated with alcohol and substance use during pregnancy.
- Early identification and intervention/support for all pregnant women who use alcohol and their partners/support systems.
- Focused intervention with high risk pregnant and parenting women and their partners/support systems.
- Timely diagnosis, assessment, and planning for children, youth, and adults affected by FASD.
- Comprehensive and lifelong intervention and support for children, youth and adults affected by FASD and their families/support systems.
- Leadership and coordination of FASD initiatives at the community, regional, provincial and national levels (p. 6)

[37] No quantitative evaluation occurred, but a working group representing the majority of the government and municipal agencies reviewed the BC Strategy. Gaps were acknowledged and addressed, which resulted in a revised strategy (BC Government, 2006).

British Columbia's 10-year FASD Provincial Plan (2008-2018) builds on BC Strategy and provides a framework for action that "includes goals, guiding principles and cross-government strategic priorities for addressing FASD" (Hunting, 2012, p. 99). In keeping with government form, the Plan presents itself as a "visionary document" that summarizes major initiatives but does not provide a comprehensive framework or evaluations of provincial initiatives. Recent critics of the 10-year plan have utilized an intersectionality-based policy analysis framework,[38] which identifies three themes: "women-centred" discourse, "risk" discourse, and "culture" discourse (Hunting, 2012). These themes are consistent with those that have emerged from this research and are addressed in the appropriate level of prevention: That is secondary level, when dealing with high risk women.

After my preliminary analysis of the BC Strategy, numerous disjunctures became apparent. One of the challenges, when evaluating the disjuncture between the provincial policy and the Strategy, is that both are "general", high-level documents. While high-level documents are essential for managing a policy issue such as FASD, reality is often different from what is described in the strategy for frontline workers, lawyers, and affected families.

During this analysis of the BC Strategy, some common themes emerged. The case law that materialized illustrates the moral and legal complexity of balancing the rights of the mother with the rights of the fetus against the moral and legal obligations of a civil society. In many of the justices' dissenting decisions, they argued that the courts do have *parens patriae* jurisdiction, but if these verdicts were exercised, the courts would need a mechanism of enforcement to protect fetuses from negative maternal behaviours such as alcohol and/or substance use. Such precedent-setting cases as *Dobson v. Dobson* (Litigation Guardian)[39] raise the issue of how far the court can address the issue

[38] Intersectionality has been used to address the experiences of those individuals who are subjected to multiple forms of disadvantage (McCall, 2005). "Intersectionality challenges the primacy of gender as an analytic category in understanding experiences of privilege and oppression" (Hunting, 2012, p. 95).

[39] (1999), 174 D.L.R. (4th) 1 (S.C.C.)

of *en ventre sa mẻre*,[40] and therefore question the application of this concept to FASD prenatal policy. Besides, one question remains: What would it take to have "a general policy discussion" about the role of policy in relation to the protection of foetuses, given the complex implications of the *parens patriae* and *ventre sa mẻre* principles?

In addition, child protection statutes were used as a mechanism for apprehending a mentally competent pregnant woman and her fetus. As in the case of *Baby R,*[41] a woman's failure to listen to her physician's advice, constituted *prima facie* evidence of her being an unfit mother and was grounds for apprehending the fetus. Also, dissenting judges specifically addressed "policy" issues around the special relationship and the appropriateness of the courts to regulate this relationship between mother and unborn fetus.

As the courts and policy makers explore fetus protection and FASD prevention there is a noticeable absence of this discussion in the FASD Strategy. Despite this absence, dissenting judges acknowledge in their written submission that the absence of policy should not interfere with the ability of a child to sue a parent *in utero*. This absence suggests that either is a reluctance to develop fetus protection policy which would be one component of a harm reduction strategy or the authors of the policy were not aware of the legal cases that have explored child issues *in utero*.

In summary, the overall goal of the provincial FASD strategy is to promote the healthy well-being of all women of child bearing age. In addition, support and services should be easily accessible for pregnant women as well as for the life course of children affected with FASD. However, it appears that biological, sociological, and psychological factors contributing to FASD need to be identified and addressed. Using a tri-level framework proposed in this dissertation and embedded within an integrated systems

[40] *en ventre sa mẻre* means in gestation, in the womb of one's mother. 100 N.W. 2d 445, 447. In the law of property, a person who is *en ventre sa mere* has the same rights as, and is entitled to the same protections as, a person who has been born. Powell, Real Property §796(3) (1949, Supp. 1995).

[41] *Baby R*. (1987, September 10). Taped broadcast, radio station, CFAH, Victoria, B.C. as cited in Maier, K.E. (1989). Pregnant Women: Fetal Containers or People with Rights. *Affilia*, 4, 8. Doi: 10.1177/088610998900400201.

theory approach such as Robinson's model, the research findings fit into a more understandable but comprehensive model that "collectively" provides more informed policy.

In general, the existing policies and interventions that are aimed at the mother cover legal, educational, assessment, and research issues. Legal initiatives focus on statutes, fetal and constitutional rights, alcohol policy (including prenatal screening), placement of infants, and treatment of mothers. Education includes awareness for the general public and women of child-bearing ages and training for mothers, family members, and professionals such as doctors, educators, and social service workers, just to name a few. Assessment should include a determination of "high risk", in addition to the provision of support services for all women. Finally, other concerns in dealing with the mother are criminalization, constitutional issues, policing pregnancies, and the impact on welfare reform.

Currently we seem to have numerous policy initiatives. However, it appears that they seem to be implemented in isolation, focusing, for example, on women of child-bearing age and high risk mothers. Initiatives are not multi-levelled and mainly consist of education and awareness programs, which is why efforts may not be working. This integrated systems model provides a way to demonstrate how all these levels and factors should relate together. When a comprehensive examination such as the one advocated for in this dissertation is used, gaps become evident and it is then possible for future efforts to address these specific areas.

Had this integrated systems model been used, more appropriate initiatives could have been implemented. The BC Strategy implies that all stakeholders are relevant at every stage in an affected individual's life, which is not the case. At particular stages, specific stakeholders should be addressed: For example, health professionals are more relevant than educators at the fetus stage. The strategy also totally ignores the issue of balance between a pregnant woman's rights and her responsibilities to the fetus.

Although education and awareness are suggested, they should ideally start in the child-bearing years and not just at pregnancy. Proper health, including nutrition and substance use/abuse, should be part of the high school health and/or physical education curriculum. Prenatal visits provide an excellent opportunity to initiate intervention for

high risk women. As well, family physicians should discuss general health issues with female teenagers, including a discussion about substance use and pregnancy.

The BC Strategy has several initiatives within the child/youth life course stage.[42] The first priority is to ensure that medical curricula include ethical and best clinical practice for diagnosis and assessment, early developmental interventions, and treatment and support of affected individuals and their caregivers.

The second priority is to explore options to enhance accessibility and suitability of current programs and services in areas relevant to the comprehensive needs of affected children, youth, adults, and their families/support systems (BC Government, 2003). In addition, the strategic priorities for 2007-2010 include exploring options to enhance the recruitment and retention of health care professionals involved in the diagnostic and assessment process, especially for rural and remote areas of the province. As well, options should be explored to enhance and improve the suitability of programs and services for children, youth, and adults living with FASD; and their families and support networks. A strategy needs to be developed for coordinating successful transition from youth to adulthood.

A gap between youth and adulthood has been identified, which has been created by the obligation of MCFD to protect individuals up to the age of 19. After this age, there is limited access and availability of resources to those affected individuals. In addition, cross-government collaboration needs to be strengthened to coordinate and integrate support networks at the community level across all sectors to provide for lifelong support and intervention, using a case management approach (BC Government, 2006).

Resources need to be provided to better equip doctors with the knowledge to detect an individual affected by maternal alcohol exposure and the willingness to refer the individual to diagnostic specialists. Subsequently, more funding needs to be provided to accredited diagnostic specialists for the equipment necessary to make

[42] An individual's development can be described as a life course beginning with fetus and continuing through infant, child, youth, and adult. An individual with FASD will require different support and services for each stage as well as transitions into each stage.

proper assessments; thereby making diagnosis more accessible. Within B.C., there are five different health regions, each with its own unique composition that might include urban, rural, remote, and Native areas and each with its own varying populations, needs, and funding. Nonetheless, the BC Strategy has identified First Nations, Métis, and Aboriginal communities as priorities for FASD prevention (BC Government, 2006).

Another priority of the BC Strategy for the child/youth stage was to explore options to enhance accessibility and suitability of current programs and services in areas relevant to the comprehensive needs of affected children, youth, adults, and their families/support systems. Individuals with FAS/E are not candidates for independent living as adults without extensive, intensive, comprehensive, and continuing supports in place, regardless of whether the affected individual had an IQ of 90 or 68 (Malbin, 2008).

FASD policy is clearly not connected together as a life cycle policy. Adults with FASD do not have dedicated funding. Research has not focused on the needs of adoptive parents or other adults in custodial positions who face enormous financial, legal, emotional, and other responsibilities or the needs of adults living with FASD with respect to residential and living support. With respect to costs in Canada, it is estimated that FASD disabilities create about $2.8 million additional direct costs over the course of an affected individual's lifetime, not including lost working potential of the individual or the family or caregivers (Thanh & Jonsson, 2009).

In general, there appear to be numerous disjunctures that become apparent when analyzing the BC Strategy as well as other FASD policies through the integrated systems model lens. One of the challenges, when evaluating the disjuncture between policy and the BC Strategy is that both are "general" high-level documents. As mentioned previously, while high-level documents are essential for managing a policy issue such as FASD, reality is often different in practice for frontline workers, lawyers, and affected families.

Currently, Canadian data suggest that it is difficult to determine an accurate prevalence rate for FASD, although estimates suggest that as many as 9 births per 1,000 will suffer from FASD. However, the Canadian government has begun to develop an action plan that will have a strong base of evidence supporting the decision to take action (Health Canada, 2006). With an understanding of the underlying factors

illustrated by an integrated systems model and an evidenced-based or logic model framework to policy making, more feasible initiatives to reduce the number of individuals affected by FASD can be implemented.

Chapter 5.

Discussion: Secondary Prevention Level

This chapter will focus on the second of the three prevention levels. At this level, the goal of the intervention is to modify those environmental conditions that increase the possibility of maternal drinking.

This chapter begins with a discussion of the risk and protective factors of FASD. A better understanding of these factors is necessary in order to propose realistic and feasible secondary level policy initiatives. I will then explore current screening tools and diagnostic criteria for high risk women. Next, I summarize general attitudes and concerns of media campaigns and legal implications aimed at "the drinking mother". I continue with a discussion of exemplar initiatives aimed at reducing or eliminating maternal drinking at the secondary level. In addition, I summarize the common themes and most promising practices from the current literature. I conclude this chapter with an examination of the characteristics of a high risk population.

FASD Risk and Protective Factors

Maternal Risk Factors for FASD

Extensive literature exists on the risk factors for FASD; however most data originate from small studies and case reviews. Furthermore no comprehensive examination of risk factors has been conducted, specifically analyzing the interactions amongst the risk factors themselves or in conjunction with protective factors. I hope to contribute to this gap of knowledge by providing a more organizational approach, one that encompasses an interdisciplinary perspective. Although I have simplified each factor into a single category, this approach does not reflect the complexity and intricacy of the factors themselves, the interactions of the factors, nor the resultant behaviours,

but it does allow for better organization and hierarchical comparison. Within this methodology, the factors have been categorized by influential elements such as health, socioeconomic status, drinking pattern, psychological profile, family social traits, and local culture and community (Appendix A). These categories of influential elements can also be organized within an integrated systems theory to illustrate the interconnectedness of the factors (Table 5.1).

Table 5.1. The Influential Element in Relation to the Systems Theory Category.

Systems Theory Category	Influential Element
Cell	Genetics
Organ	Genetics Health
Individual	Health Psychological Profile Socioeconomic Status Drinking Pattern
Family	Socioeconomic Status Drinking Pattern Family Social Traits
Community	Socioeconomic Status Local Culture and Community (Demographics)
Society	Culture and Community (Demographics)

Levels and Patterns of Alcohol Consumption

There are limited Canadian statistics on pregnant women drinkers. Studies estimate that somewhere between 10% to over 50% of women consume alcohol during pregnancy and that approximately 1.9% engage in binge drinking (defined as five or more drinks on one occasion) (Drabble et al., 2011, p. 7). Senikas (2011) found that pre-pregnancy binge drinking was a strong predictor of both drinking and binge drinking during pregnancy. It has also been determined that in order to develop better policy, prevention, and intervention for this problem, further research needs to be conducted on the motivations for drinking during this crucial period. Research indicates that in addition to women from underprivileged backgrounds, drinking mothers also include “women over 35 years of age, ‘social’ drinkers, women who are highly educated, women with a history of sexual and emotional abuse, [and] women of high socioeconomic status” (Senikas, 2011, p. 258).

Studies have also suggested that alcohol ingestion during pregnancy exceeding 3 to 5 drinks per day can increase the risk of having an infant with FAE thirty to 50% (Niemela, Hamesmaki & Ylikorkala, 1991). Although no definite threshold has been identified, researchers believe it is a dose-response relation (Sood et al., 2001). Risk also seems to be elevated when drinking begins at an early age (NIAAA, 2000).

Although maternal drinking is the cause of FAS and/or related effects, alcohol-consuming mothers can produce children with a variety of effects, ranging from no effects to severe or even fetal death (O'Leary, 2013). Niccols (1994) reported that the gravity of alcohol exposure depends on the amount, the drinking pattern, and developmental stage of the embryo when alcohol was consumed. Many researchers reiterate the same message: High blood-alcohol concentration is related to timing, pattern, and frequency of binge drinking (Jacobson & Jacobson, 1994; Sood et al., 2001).

Most of the literature confirms that the primary cause of women giving birth to children with FAS is the consumption of large quantities of alcohol in heavy, episodic patterns (drinking four or more drinks on one occasion or seven or more drinks per week) during pregnancy (Abel & Hannigan, 1995; Bagheri, Burd, Martsolf & Klug, 1998; May et al., 2004). Current research also indicates that there is a misconception that *abstinence* refers to "an 'acceptable' level of alcohol consumption", one that helps oneself to relax and socialize, and that it does not mean "not drinking at all" (Tutain, 2011, p. 321). There is also numerous cases of educated women who drank while pregnant and gave birth to healthy babies (Senika, 2011). These "mixed messages" give the impression that FASD is a "mutation" rather than a result of prenatal ethanol exposure.

Biological Factors

Research indicates other major risk factors among women who give birth to children with FAS include high gravidity and parity[43] (May et al., 2005), tenuous marital status (Leonardson & Loudenburg, 2003; May et al., 2004), use of tobacco and other drugs (Bagheri et al., 1998), use of illicit substances (Abel, 1990; Niccols, 1994), low socioeconomic status (SES) indicators (such as low education, unskilled job classifications), low level of religiosity (May et al., 2004), Aboriginal ethnicity (Robinson et al., 1987), and cohabitation with a heavy-drinking male (Sood et al., 2001). In addition to prenatal alcohol exposure and smoking, maternal risk factors include poor health resulting from poor nutrition and diet (Abel, 1990; Bagheri et al., 1998), all contributing to physiological stress (Chambers, 2011), low pregnancy weight (Abel, 1990), and a history of spontaneous abortions (Abel, 1990). Although no definitive amount of alcohol during pregnancy has been associated with impact on infant development, research does indicate that with each additional ounce of alcohol consumed per day, the risk of spontaneous abortion increases by approximately 25% (Russell & Skinner, 1998). Another major risk concern is hypoxia, which can result from impaired placental or fetal blood flow (Abel & Hannigan, 1995). Other research demonstrates that significant predictors include women with more than one child who have had short intervals between the births of their children (Abel, 1990; Niccols, 1994).

As well, advanced maternal age has been determined to be a characteristic of women who drink during pregnancy. Jacobson et al. (1993) discovered that neonatal adverse effects were related to maternal age; no significantly affected infants were born to women under 30 years who were moderate to heavy drinkers. Conversely, for older women who were moderate drinkers the risk of infant impairment increased 2 to 5 times (Jacobson et al., 1993).

[43] Gravity means “the number of times a female has been pregnant”; whereas, parity means “the number of times a female has given birth counting multiple births as one and usually including stillbirths.” Retrieved November 7, 2013 from http://www.merriam-webster.com/medical.

Additionally, being a victim of alcohol embryopathy or having an alcoholic mother increases the likelihood of maternal drinking while pregnant (Rouleau, Levichek, & Koren, 2003). May et al. (2005) indicate that some mothers of FAS children appear to have FASD themselves, where their alcohol abuse may originate in part from behavioural traits associated with FASD such as impulsivity and poor judgment. Furthermore, studies which determined smaller average head circumference among FAS mothers, as well as heavier drinking among maternal grandmothers of FAS children, raise questions about intergenerational prenatal alcohol exposure and damage (Kvigne et al., 2003). In addition, untreated or under-treated mental concerns have been identified as maternal risk factors (Abel, 1990; Chudley et al., 2005). Stratton et al. (1996) reported that low self-esteem, depression, and sexual dysfunction contribute to the woman's likelihood of drinking when pregnant.

May et al. (2004) suggest that smaller women are more apt to having lower drinking thresholds for producing FAS symptoms than larger women. Notwithstanding, heavy alcohol consumption can interfere with regular eating habits and result in less body mass and poor nutrition. May et al. (2004) found that women who bore children with FAS or partial FAS had a lower body mass index (BMI) than those women whose children did not have FASD, suggestive of a combination of lower alcohol tolerance and less body fat.

Past and recent studies have identified that having a previous child with FAS places the woman in an extremely high risk category for having additional children with FAS, if drinking continues during subsequent pregnancies (Abel & Hannigan, 1995). Therefore, FAS and related effects are useful risk markers for living siblings and subsequent pregnancies. This high risk population of women who have had a child with FASD represents an excellent research opportunity for examining transgenerational social determinants (Bagheri et al., 1998; Burd & Wentz, 1997).

Sociological Factors

In the general literature on alcohol abuse, having alcohol-abusing parents, poor life goals, and few interests have been correlated with maternal drinking (Day, Cottreau & Richardson, 1993; Schlesinger, Susman & Koenigsberg, 1990; Shore & Pieri, 1992;

Wilsnack, 1991). Women who drank were more likely to be less educated, have less access to transportation, and have alcohol dependence in their families of origin. Lex (1992) noted higher rates of mental illness, family violence, and sexual abuse in substance-dependent women, proposing that many women self-medicate mental illness and other family problems by using substances. There is also this stereotypic perceptions of FAS mothers which includes low education, low SES, and substandard patterns of food consumption, which affect alcohol metabolism, hence blood alcohol concentrations resulting in teratogenic effects on the fetus (May et al., 2004).

Results from an extensive survey conducted by the four-state (Minnesota, Montana, North Dakota, and South Dakota) FAS consortium indicated that women who reported their race or ethnicity as White were less likely to drink than non-Caucasian women (Leonardson & Loudenburg, 2003). In addition, women who reported sexual or physical abuse were more likely to drink during pregnancy than women who did not report abuse. As well, alcohol consumption among family and friends has been determined to have a profound impact on female drinking (May et al., 2004).

Many women with FAS children live within a social and cultural milieu that tolerates, ignores, or is unsuccessful in dealing with problem drinking (May et al., 1983). For instance, such women often have parents, siblings, and friends who are problem drinkers. In addition, it is common for FAS children and their siblings to be in foster care or adoptive placement because high risk mothers are generally unable to care for their children adequately resulting in multiple custody changes (Clarren, Carmichael-Olsen, Clarren & Astley, 2000; Sood et al., 2001). As well, mothers of FAS children are at increased risk for premature mortality due to their drinking and lifestyle (May et al., 1983).

Risk is also heightened by Aboriginal and low socioeconomic status (Abel, 1990; Niccols, 1994). A study of maternal risk factors in the Western Cape Providence of

South Africa indicated that FASD mothers had fewer social resources, such as education, income,[44] or spirituality than non-FASD mothers (May et al., 2005).

Throughout the literature, a wide variety of maternal risk factors have been identified, however, the encompassing theme is consistent: No one factor makes a pregnant woman drink alcohol. It appears that a complex network of biological, psychological, and sociological factors result in increased maternal drinking.

With a basic understanding of maternal risk factors, it would appear to be possible to focus policy strategies on these high risk women. In most cases, multiple factors have contributed to a woman's maternal drinking; therefore more specific policy to mitigate these factors hypothetically should reduce FASD occurrence.

Maternal Protective Factors for FASD

Current literature identifies genetic, health, and demographic influential elements as protective factors for FASD (Appendix B). Regarding protective genetic factors, two have been linked to FAS. May et al. (2004) identified one pattern of alleles within the liver isoenzyme polymorphisms and alcohol dehydrogenase (ADH) 2*2, which has been suggested as being protective. Genetic studies have also shown that maternal ADH2*3 alleles, which code for a more effective alcohol dehydrogenase enzyme, decrease the risk associated with having a child with FAS (McCarver, Thomasson, Martier, Sokol, & Li, 1997). A third protective factor ADH1B*3 appears promising (Jacobson & Jacobson, 2007). This allele suggests that although this pattern is relatively rare, it is found in higher prevalence in non-FAS mothers and their children in South Africa than among mothers of children with FAS. Studies indicate that maternal and fetal genotype can influence susceptibility to alcohol teratogenesis (Chasnoff, 1985; Christoffel & Salafsky, 1975; Streissguth & Dehaene, 1993).

[44] Ironically women are paid in alcohol for their work (May et al., 2005).

Studies of fraternal twins who experience the same effects from alcohol exposure suggest that genetic variables may also be related to FAS (Abel, 1990). In addition, differential sensitivity to FAS and related effects in dizygotic twins, as well as a high concordance for FAS/ARBDs among monozygotic twins, suggest a genetic basis for individual vulnerability to the teratogenic effects of alcohol (Streissguth & Dehaene, 1993).

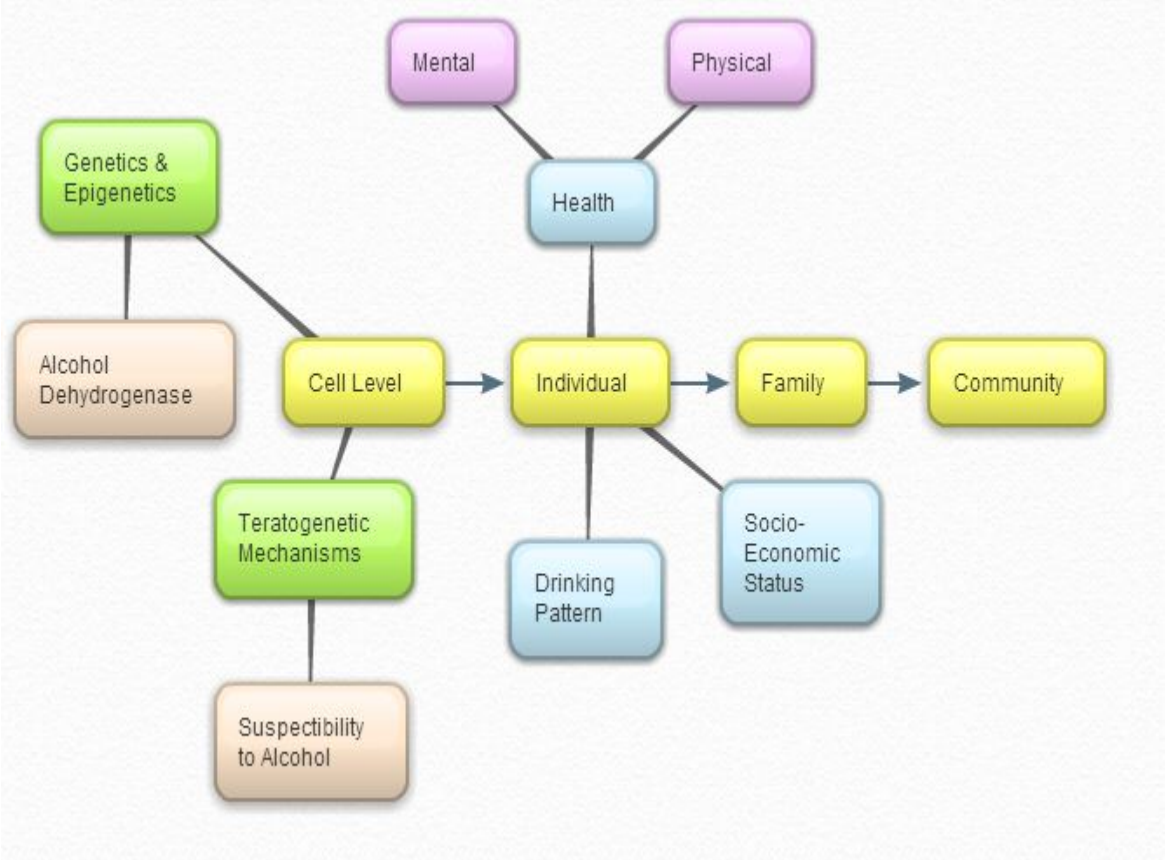
Other key protective factors were low gravidity and parity, larger body size, and adequate nutrition such as maternal folic supplements (Chambers, 2011; May et al., 2005). In addition, animal studies have demonstrated that choline supplements administered postnatally appear to protect as well as improve some of the behavioural effects of maternal alcohol ingestion (Chambers, 2011).

Many studies have discovered that besides biological, genetic, and psychological traits, there are a number of sociological protective factors for maternal drinking including strong cultural support for abstinence or light drinking, a non-drinking male partner, higher education, higher income, and religiosity (Blume, 1990; Chambers, 2011; May et al., 2004; Viljoen, Carr, Foroud, Brooke & Ramsay, 2001; Viljoen et al., 2002). Leonardson and Loudenburg (2003) determined that married women were less likely to use alcohol during pregnancy because of the superior social and financial support they receive and of the greater possibility of their pregnancies being wanted. In conclusion, the best preventative mechanism to decrease the likelihood of maternal drinking would be a combination of biological and sociological protective factors.

Interactions Between Risk and Protective Factors

To illustrate the interactions between the maternal risk and protective factors underlying fetal alcohol spectrum disorder, I created the following schematic diagram (Figure 5.1). The diagram is based on factors at the cellular, individual, family unit, and community levels to demonstrate the interconnectiveness of these factors related to the problem. Protective factors, such as alcohol dehydrogenase (ADH) and susceptibility to alcohol teratogenesis are found at the cellular level. Conversely, negative factors such as teratogenic mechanisms of FAS, including hypoxia and free radical damage, are micro and operate on the level of cellular impact (Abel & Hannigan, 1995).

Figure 5.1. Interaction Between FASD Risk and Protective Factors.



At the individual level, three categories are significant for maternal drinking: drinking pattern, SES, and health including physical and mental factors. Many of the individual-related factors interact with the family, as well as with the community. It is the combination of biological, psychological, and sociological interactions which contribute to the outcome: Maternal drinking.

Intervention Issues

Now that I have discussed the contributing factors for FASD, I will examine the common issues related to intervention. These issues will relate to screening tools, research, education, legal, and treatment initiatives.

Diagnosis and Screening Tools

Screening tools are the first theme of intervention. *Screening tools* refers to instruments based on a set of criteria that are used to diagnose FAS. An extensive list of common screening tools includes the AUDIT, TWEAK, T-ACE, CAGE, S-MAST, CRAFFT, Ten Question Drinking History (TQDH), 4-Digit Diagnosis Code, and the Behavioural Risk Factor Surveillance System (BRFSS) (O'Leary, 2004). The purpose of these instruments is to gather reliable information about maternal drinking that is vital to establishing an accurate diagnosis. However, I question the reliability of a diagnosis where only one such method is used, particularly when the sole source of information is self-report data. In addition to self-report surveys, diagnoses need to be based on multiple sources including, for example, biological tests such as utero ultrasounds (Escobar, Bixler & Padilla, 1993) or biochemical markers (Cook, 2003).

Another concern with screening tools is whether they capture the complete population: Are people misdiagnosed (capturing too much of the population) or under-diagnosed (identifying an under-representation of the population)? In either case, one must evaluate the reliability and validity issues with regard to the specific screening tool being utilized. In addition, I question why so many screening tools have been developed. This multiplicity of tools seems to indicate a lack of consensus about what constitutes an appropriate measuring instrument.

Research

Research has provided the necessary background to recognize and identify characteristics associated with FASD leading to better diagnostic methods and experimentation to validate these methods. New research has resulted in better diagnostic tools such as gender and culturally appropriate instruments for screening of all women during the child-bearing years (Russell et al., 1994). In addition, with the advancement of technology, routine procedures can include ultrasonography (Handmaker et al., 2006) and the collection and analysis of biomarkers (Goodlett, Horn, & Zhou, 2005). Because a FAS diagnosis is often confirmed by self-report information, it is beneficial to verify with additional methods, which now can be quantified by these new procedures. Medical reports may be inaccurate or the woman may not accurately recall

the amount or frequency of alcohol consumed during pregnancy; therefore biochemical markers such as gamma-glutamyl transpetidase and mean red blood cell volume can be measured and used to validate the amount of alcohol in pregnant women (Stoler et al., 1998). Regardless of the approach, the overall goal is to reduce the amount the pregnant woman's drinking and to secure a diagnosis, with the intent of intervention, at the earliest possible moment.

Education

Education is the third area of concern with regards to preventative practices and policies. Many educational avenues exist and, within the secondary prevention level, education may come from "women-centred" health and support services in the form of awareness campaigns. However, the success of such campaigns relies on women's incentives and desires to change their behaviour (Basford et al., 2004). Programs such as community-based initiatives that target pregnant high risk women appear to be more effective when the individual sets their own goals (Chang et al., 2005). Studies indicate that other successful educational strategies employ motivational interviewing (Handmaker et al., 1999). Important to be aware of in this context, is that new research indicates that *shaming* (directed at the "drinking mother") can actually increase the risk of recidivism and, hence, the risk of child abuse and neglect, or continued alcohol use. Therefore, awareness of the negative effects of shaming should be taken into consideration when implementing policy and practice.

In addition, the B.C. government is sponsoring an alcohol and pregnancy awareness campaign. This educational program consists of warning signs, posters, magnets, public service announcements, etc. This awareness campaign will be evaluated in the near future by researchers at the University of the Fraser Valley to determine if this strategy is effective in reducing alcohol during pregnancy.

Law and Treatment Approaches

The fourth category of concern is the legal implication to the drinking mother. Very little is being done in the investigation of the efficacy of bringing legal action to bear on the problem; however, this field could be the focus of more research and

implementation. Currently, the law can force substance users to attend drug or alcohol rehabilitation and treatment. Mothers who already have a child with FAS may constitute a population where intervention could be enforced.

Another facet of legal implications is the usage of warning labels. In Canada, the Yukon is the only jurisdiction requiring warning labels on alcohol beverages. However, labels were implemented because of a policy decision rather than legislation (Health Canada, 2000). In British Columbia, some municipalities have by-laws mandating alcohol retail stores and alcohol serving establishments to post information on the effects of alcohol use and pregnancy.

The final category of concern with regard to the drinking mother and FAS is treatment. Researchers found that selective interventions that targeted high risk individuals appear to be more successful (Floyd, Ebrahim, & Boyle, 1999). Project CHOICES (Changing High Risk Alcohol Use and Increasing Contraception Effectiveness Study) is aimed at preventing alcohol-exposed pregnancies among high risk women in special community settings such as jails, alcohol and drug treatment centers, gynecology outpatient clinics, and country department community health centers (Floyd et al., 1999). Treatment included assessment, personalized feedback, goal setting, taking action, and follow-up.

Nutritional interventions during pregnancy can also be undertaken in high risk populations that are most likely to give birth to children with FASD (Goodlett et al., 2005). Treatment might include antecedent supplementation with antioxidants, targeted treatment with confirmed drinkers with 5-HT (5-hydroxytryptamine) agonists or D-NAP (a form of amino acid peptide). An alternative strategy, which has been successful in reducing consumption of heavy drinkers, involves screening combined with a brief intervention based on FRAMES[45] (Yahne & Miller, 1999). Regardless of the intervention, it appears that five characteristics are consistent: (1) identification of at-risk women, (2) assessment of drinking behaviours, (3) provision of information on the

[45] FRAMES stands for: *feedback*, *responsibility*, *advice*, *menus*, *empathic*, and *self-efficacy.* Retrieved November 18, 2013 from http://www.ncbi.nlm.nih.gov/books/NBK64963/.

harmful effects of drinking, (4) method of delivery that facilitates decisions to adopt healthier drinking behaviours, and (5) monitoring of changes or progress (Masotti, Szala-Meneok, Selby, Ranford, & Van Koughnett, 2003).

In conclusion, no one intervention, besides absolute abstinence, can prevent all alcohol-related birth defects. An integrated approach focusing on screening tools, research, education, legal approaches, and treatment interventions can significantly reduce the risk of FAS and other prenatal alcohol-related harm to children. Preventative and intervention mechanisms should include a combination of biological and sociological factors that will decrease the likelihood of maternal drinking. Research needs to continue, focusing on all facets of connection between pregnant women and alcohol consumption, decreasing the gaps in knowledge, and determining ways to infiltrate the cycle. Finally, education should focus on encouraging healthy lifestyle choices which result in healthy babies.

Current "Most Promising" Programs and Policies

The drinking mother discourse is currently being heard and better understood and, increasingly, the factors contributing to maternal drinking and hence FASD are being acknowledged (Wood, Hellsten & Martin, 2011). In conjunction with this developing understanding, research has also been aimed at uncovering the barriers that prevent women from receiving treatment (Poole, Gelb, & Trainor, 2008). The now widely accepted categories of barriers to treatment and care include personal, community or social barriers, and structural and systematic barriers (Poole et al., 2008; Poole & Urquhart, 2010). New initiatives are attempting to eliminate these barriers by providing centralized integrated services.

The recurring themes that emerge from the literature include women-centred care, gender-informed harm reduction, service integration, and choice. As well, promising principles acknowledge and explore the links between women abuse, substance use and other health, financial and social concerns, and mental ill health (Cory, 2011; Parks et al., 2008). In addition, more promising practices address a diversity of needs of different subgroups of women by tailoring the screening, identification, and intervention, as well as applying harm-reduction philosophy and practice (see Parks et al., 2008)

(Table 5.2). Besides the previously mentioned main elements of women-centred care, new prevention initiatives include a four-part model: broad awareness, discussion of pregnancy and alcohol use, specialized support of pregnant women with alcohol problems; and postpartum support (Poole, 2008).

Table 5.2. "More Promising" Policy or Program Initiatives Focusing on Screening.

Initiative	Description	Source
Help Kit Training - Alberta Health Services	Health reform - recognizing gender differences, research focus on women and substance use, emphasis on FASD prevention/healthy birth outcomes, enhanced services for women (reducing barriers and increase awareness), help kit training - examine personal values and beliefs, learn about the effects of alcohol, drugs and tobacco taken during pregnancy, key issues and barriers for women, provides screening instruments and guidelines for intervening, explores motivation and introduces an intervention approach based on stages-of-change model.	Scurr & Sellwood, 2009, p. 28
SBIRT - screening, brief intervention, referral to treatment - Colorado	Screening - to identify people at risk for a condition. Brief intervention - low-intensity, short-duration counseling for those who screen positive based on motivational interviewing techniques. Referral to treatment - for those who have more serious problems. SBIRT is designed to identify people with nondependent use and to provide effective intervention prior to the need for more intensive treatment.	Swenson, 2009, p. 123
Medicine Wheel (MW) Tools and the Nogemag model	Offers a relational approach to screening and intervention that is grounded in the traditions of a Mi'qmaw First Nation community "as service and health professionals we have to connect with our clients' identity if we are to help with their healing". The MW tools include the MW student index (a screening and referral tool), the NW developmental history tool, a semi-structured parent interview, the MW difference game cards for needs assessment and goal setting, and the MW community development tool useful within a community system for problem mapping and strategy session with parents or teachers.	Cox, 2009, p. 361

Another perspective on addressing the complex nature of FASD is the community-based approach, which consists of programs that modify "the community structures, processes, and policies" (Baker & Brownson, 1999, p. 8). Some of the programs target substance abusing women and include drug treatment and counselling programs (Basford et al., 2004) (Table 5.3).

Table 5.3. "More Promising" Policy or Program Initiatives Focusing on Treatment and Acute Care Policy and Programming for Women with Substance Abuse Problems

Initiative	Description	Source
Burnaby Centre for Mental Health and addictions	100 bed facility providing comprehensive, inpatient care for people who are living with complex psychiatric and substance use problems in the context of homelessness, involvement in the criminal-legal system, and other challenges.	Salmon, Krausz & Schutz, 2010
CCD Trauma Program for Women	Not specific to FASD, women with complex substance use and mental health problems who require long-term residential treatment prior to returning safely to the community.	Salmon et al., 2010
Healing Ourselves: Mothers Recovering from Grief and Loss in Vancouver's Downtown Eastside	Healing Ourselves Mothers Empowerment study, in which researchers, service providers, and women living in the Downtown Eastside have come together to develop and evaluate an evidence-based intervention to provide recovery support to mothers with concurrent substance use and mental problems who have permanently lost a child due to apprehension or death.	Salmon et al., 2010
Psychotherapy	Treatment of mental disorders, provide understanding to problems, modify behaviours, improve emotional stability, reduce distressing experiences, change cognitions, resource for support and treatment, and facilitate position changes. Structure of therapy - individual needs and strengths, duration or length of session, consistency, barriers/limitations and sustainability. Adopting a systemic approach - mental health, abuse and trauma, environmental barriers, presenting problems related to primary disability and external supports.	Douglas, 2009

Regardless of the perspective or model used to address FASD, the complexity of the problem is being acknowledged and a growing list of community-based "promising practices" is emerging (Table 5.4). For example, New Choices is an exemplar program based in Hamilton, Ontario. In addition to women's services which address addiction, education, parenting, and life skills, it provides children's services on-site including child enrichment programs, developmental screening and assessments, speech and language services, and referrals to additional required services (Millgan 2009).

Table 5.4. "More Promising" Policy or Program Initiatives which are Community-based.

Initiative	Description	Source
Phoenix Transition Society's Phoenix House (Prince George)	"Operates a shelter with a supportive environment for women and their children who are in crisis".[46] Besides shelter, other services are provided including "short term supportive counselling, referral to appropriate agencies, assistance in attending appointments and in finding housing, and follow-up support for women after they leave the Transition House".	Rutman, 2011, p. 25
FASD Collaborative Family Care Homes Project (Victoria)	It was a 3-year demonstration project.[47] The key objectives were: "to provide support to mothers who have FASD and their children by housing them in a family home environment, to support mothers whose children would otherwise be apprehended with the opportunity to raise their children, to create a stabilized, structured environment where women and children will have better opportunities to access informal and formal resources in the community, and to provide parenting role models and support for moms and their newborns/children".	Rutman, 2011, p. 24
Pregnancy Outreach Program (POP)	Any program whose role is to provide support, services, and education, targeted to B.C.'s peri-natal families who face challenges. Provide prenatal and early parenting support to women and their families who experience health or lifestyle challenges during pregnancy, birth and the transition to parenting.	The BC Association Of Pregnancy Outreach Programs[48]

[46] See http://www.phoenixhouse.ca/index.php for additional information.

[47] See http://www.peers.bc.ca/images/FASD-CFCareHomes_news09.pdf for more information.

[48] See http://www.bcapop.ca for more information.

Initiative	Description	Source
Healthy Babies Program	Helps mothers build and maintain healthy and independent lives, assures children are in safe and stable homes, and prevents future births of alcohol- and drug-affected children. Offers mentorship through the implementation of an In Home Visitation program. Offers advocacy and support to assist clients with breaking service barriers, obtaining treatment, and guiding individuals to make healthy lifestyle changes. Program activities include: participation in drug and alcohol residential treatment or day treatment services, assessment services, crisis intervention services, family stabilization, voluntary participation by clients, referrals to existing community services, goal setting with clients, development of client service plans, case management, reflective supervision and support program mentors, and assistance with obtaining stable housing.	Buckskin & Standing Alone, 2007, p. 31
OARS Approach (Own Act and Reflect)	Based on a holistic model of intervention that invites women to Own, Act, and Reflect on their wellness. Proactive and draws on the strengths, abilities, and self-knowledge of the woman, recognizing that they are very much the experts in their journey towards health and wellness. This model attempts to integrate the broader knowledge of the First Nations culture, as we have come to perceive it, local community knowledge, and health promoting knowledge about FASD prevention and maternal wellness. OWN speaks to the recognition and ownership of the problem or issue that is standing in the way of a women's wellness - it invites the woman to own this problem herself. ACT addresses the accountability and responsibility that one must accept in order to be able to move forward, for it is in the doing that we are changed. REFLECT identifies the subjective process that caused a person to go inward and allows that person to honor who they are and to monitor their becoming.	Prince & Salmon, 2007, p. 71
Making Our Voices Heard: A Photovoice Exhibit by Mothers Whose Children are Living with FASD	Photovoice has three main goals: (1) to enable people to record and reflect their community's strengths and concerns; (2) to promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs, and (3) to reach policy makers.	Badry, Hache, Salmon, & Wright-Felske, 2013; Lauer & Kay, 2009

Initiative	Description	Source
Moms - Moms Mentoring Moms	Confidential, anonymous meeting for women who identify addiction as a barrier that relates to parenting Program provides support to women: pregnant and drinking/using, women dealing with MCFD apprehensions issues, and women raising children with FASD and needing extra support. Deliverables: reduce unnecessary involvement with foster care system, support women to reduce intake during pregnancy, connect isolated women and families with the community, build capacity of women to mentor other women and education around FASD, parenting, and life skills. Philosophy - reduce stigma and shame, recovery focused, addiction as a medical condition, meet women where they are at, non-judgmental attitude, anonymity and safety, and everyone has something to give – mentorship.	Christie, Fawkes & Pawson, 2009
Parent-Child Assistance Program (PCAP)	When case management isn't enough. To prevent future births of alcohol- and drug-exposed children. An intensive 3-year home visitation intervention for pregnant and parenting, alcohol-drug abusing mothers. "Think younger" - all clients who have FASD are not alike -- understand client's level of functioning - revise expectations based on client's level of functioning: set reasonable goals. Relational theory - positive, trusting relationships are critical. Protective payee - clients with FASD often have a poor idea of how money works. Motivational theory - motivational interviewing (MI) - is build on the principle that people do not respond well to a demand for change or an attack on current behaviour; teaches people to examine their behaviour, think about ways in which they are uncomfortable with what they are currently doing, and get motivated to make changes. Self-efficacy theory - your belief in your ability to accomplish the behaviours required to produce the outcome you desire - your expectations about self-efficacy are influenced most powerfully by your own history of accomplishment. Harm reduction theory - the goal is to reduce harmful consequences of the habit for the parent and the children and reinforce any step in the right direction.	Grant, Huggins, O'Malley & Whitney, 2009, p. 332

Initiative	Description	Source
Breaking the Cycle	A mother-child framework to reduce risk for children prenatally exposed to alcohol. -a collaborative, community-based response, -a comprehensive, integrated, cross-sectoral system response, -prevention through early identification, -improved parenting skills and the prevention of child maltreatment, -single access model with street outreach and home visitation components, -evaluation: engagement, maternal health, parenting, child development and well-being. Issues addressed: eating disorders, self-harm behaviours, partner abuse, emotional/psychological problems, poverty.	DeMarchi & Racine, 2009, p. 345
Collaborative Circle of Care	Facilitate integrated service delivery from a family focused, Collaborative Circle of Care model that insures culturally congruent and developmentally appropriate case coordination. Facilitate community design of systems to include mentors, natural helpers and elders who can increase the frequency and duration of support. Create and demonstrate respectful integration of professional and community members and volunteers. Conduct community readiness assessments. All services proceed from an understanding of the barriers that come from shame, blame, grief, and denial. The approach is multigenerational drawing on the strengths of extended family and community. Cultural congruence is imbedded throughout all services and respect is paid to eliminate stigma and judgment. Case coordination reflects family focus and utilizes forms and delivery strategies that respect this focus and conform to laws of confidentiality.	Hartness & Kuerschner, 2011, p. 235
Healthy Communities, Mothers and Children	Postpartum interventions in Aboriginal communities, both urban and rural.	George et al. (2007).
Virtual Communities	Project called Moving Forward on Improving Substance Treatment and Support for First Nations and Inuit Women in Canada - funded by the First Nations and Inuit Branch of Health Canada. Improving substance use treatment and support for First Nations and Inuit Women who are at risk of having a child with FASD.	Poole, 2011

Initiative	Description	Source
Ethical programming: Towards a community centered approach to FAS, mental health, and addictions programming in aboriginal communities	Provincial government initiative. Moral governance model - shift away from political and economic decision-making. Health and healthcare is a human right therefore, the actions of any healthcare system must be to ensure the safety of those most susceptible to harm. Aboriginal worldviews. Holistic view of the individual, family and community. Intergenerational, relational, interconnected. Responsibility and accountability.	Tait, 2009, p. 165

Another very successful program is Breaking the Cycle (BTC) originating in Toronto, Ontario. This program is "one of Canada's first early identification and prevention programs for pregnant women and mothers who are using alcohol or other substances, and their young children" (Motz et al., 2006, p. iii). BTC offers individual and group addiction treatment, parenting programs, licensed child care, child developmental services (including screening, assessment and intervention), health and medical services, FASD diagnostic clinic, mental health counseling, food supplement program, case management, parent-infant counseling, home visitation, pregnancy outreach, support around instrumental needs (including food, clothing, and transportation), and support for employment and probation and parole services (DeMarchi & Motz, 2007). One of the reasons for this program's success is its focus on the mother and the mitigating factors that contribute to her substance use.

More locally, in Vancouver, British Columbia, the SHEWAY program exists. SHEWAY, supported by the Vancouver Native Health Society, provides comprehensive health and social services to women living in Vancouver who are either pregnant or parenting children less than 18 months old and who are experiencing current or previous issues with substance use.[49] It operates in a client-centered, woman-focused environment and creates positive relationships with women based on trust and mutual respect. The services provided are delivered through both outreach and drop-in and

[49] Retrieved March 2007, from www.vnhs.net/Sheway-2004.doc

include food and nutrition services, primary health care services, counseling services, healthy child development, advocacy, community education, and fundraising.[50] These programs can serve as a model for dealing with the social issues of substance use in pregnant women as maternal drinking is not an isolated phenomenon.

Characteristics of a High Risk Population

The analysis of the serious and violent offender data indicated that 56% of the population of incarcerated youth (*N* = 517) had foster care placement sometime in their life; of which more than 86% of the 289 offenders had a clinical diagnosis of FASD. This finding suggests that it is likely some distribution of individuals with FASD, due to the secondary disabilities, can be found in the care of the ministry. Therefore, I took the opportunity to investigate another high risk population for FASD; I analyzed police data and summarized the characteristics.[51] The majority of females having contact with police were between 20 and 40 years of age (Table 5.5). These females would likely have negative social factors and be guardians who are incapable of providing the necessities for their children (Table 5.6).

Table 5.5. Age of the Individual at Time of Police Contact

Age (years)	City A	City B	City C
Under 10	13	13	21
11-20	9	15	18
21-30	18	23	19
31-40	25	13	28
41-50	8	21	15
51-60	1	8	5
61 or older	0	1	3
Age not reported	39	68	69

[50] Ibid.

[51] PIRS data, specifics discussed in methodology chapter. This high risk population included females who had contact with police for an incident that involved a code of AG0001 - The Child Welfare Act.

As can be seen, a large number of females were under the age of 10 and between the ages of 11 to 20. These would be individuals who are under the care of ministry and are probably breaching established conditions or exhibiting behaviour that could not be controlled by the designated guardian (Table 5.6). In either case, the individual under the age of 19 is apprehended back under the care of the ministry.

Table 5.6. Age of Individual with the Highest Frequency of Police Contacts within the 4-Year Period.

City A	City B	City C
33 years - 5 contacts	43 years – 5 contacts	32 years – 8 contacts
30 years – 4 contacts	42 years – 4 contacts	41 years – 6 contacts
37 years – 4 contacts	23 years – 4 contacts	8 years – 5 contacts

Age did not seem to be a factor in determining whether an individual had repeated contacts with the police (Table 5.7). City A had the fewest cases of recidivism, with only two contacts by a 21-year-old and a 25-year-old. City B had the most repeated contacts, with females ranging from 22 years to 46 years, with the majority of individuals being in their forties.

Table 5.7. Cases of Recidivism: Age of Individual and the Number of Police Contacts within the 4-Year Period.

City A	City B	City C
25 years - 2	22 years - 2	11 years - 2
21 years - 2	33 years - 2	22 years - 2
	43 years - 2	32 years - 2
	43 years - 2	41 years - 2
	45 years - 3	60 years - 2
	46 years - 3	
	46 years - 3	

Regardless of the city examined, the subject of the AG0001 Code (Child Welfare Act) was the complaint or the subject of the complaint in the majority of police contacts (Table 5.8). A number of women were reported as witnesses, 11% of the cases in City A, 5% in City C, and 1% in City B, respectively. In City B and C, the female (or subject of the call) was reported as a victim in three instances. Surprisingly, intoxication was only noted in a small number of cases; however, this may be due to coding and reporting errors.

Table 5.8. Most Common Categories of Police Contact (calculated % of police contacts) within the 4-Year Period.

Category of Police Contact	City A	City B	City C
Subject of Complaint	36 (37.5)	49 (42.2)	48 (27.0)
Complaint	36 (37.5)	60 (51.7)	56 (31.5)
Witness	11 (11.4)	1 (0.1)	9 (5.1)
Registered owner of vehicle	7 (7.3)	1 (0.1)	3 (1.7)
Intoxicated	1.0	1(0.1)	8 (4.5)
Suspect chargeable	2 (2.1)	0	4 (2.2)
Suspect	2 (2.1)	0	0
Victim	0	3 (0.3)	3(1.7)
Driver of vehicle	1.0	0	1 (0.6)
Total	96*/114**	116*/163**	178*/181**

* indicates the number of cases where information was provided.
** indicates the total number of cases when AG0001 code queried.

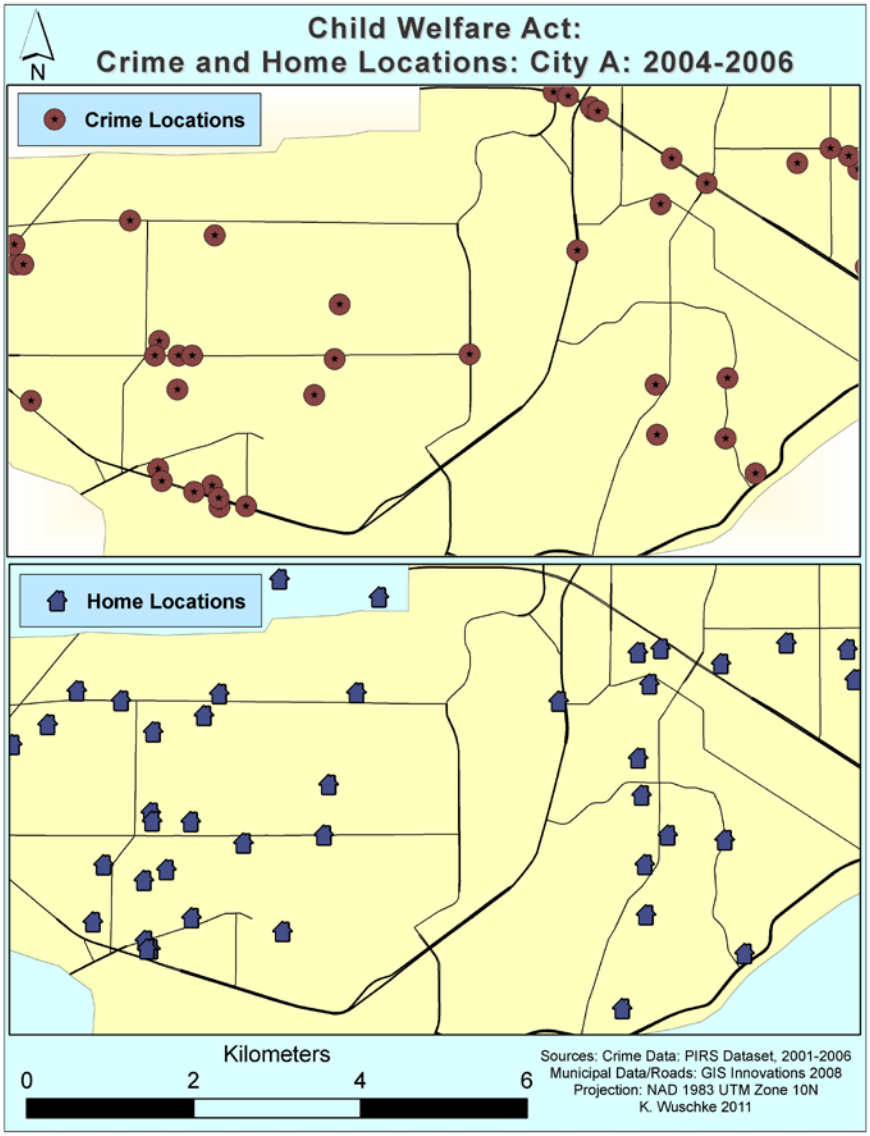
The majority of the time police were called to non-residential locations in response to the Child Welfare Act (Table 5.9). In both City A and City B, only one of the repeat calls was to the subject's home. In City C, two separate occurrences were at the same home location.

Table 5.9. Frequency of Location of Police Contact Based on the Child Welfare Act.

Frequency	City A	City B	City C
1	22	35	16
2	16	24	21
3	5	6	15
4	4	7	4
5	1	2	2
6	1	1	1
7	0	1	1
8	1	1	1
10	1	0	0
17	0	0	1

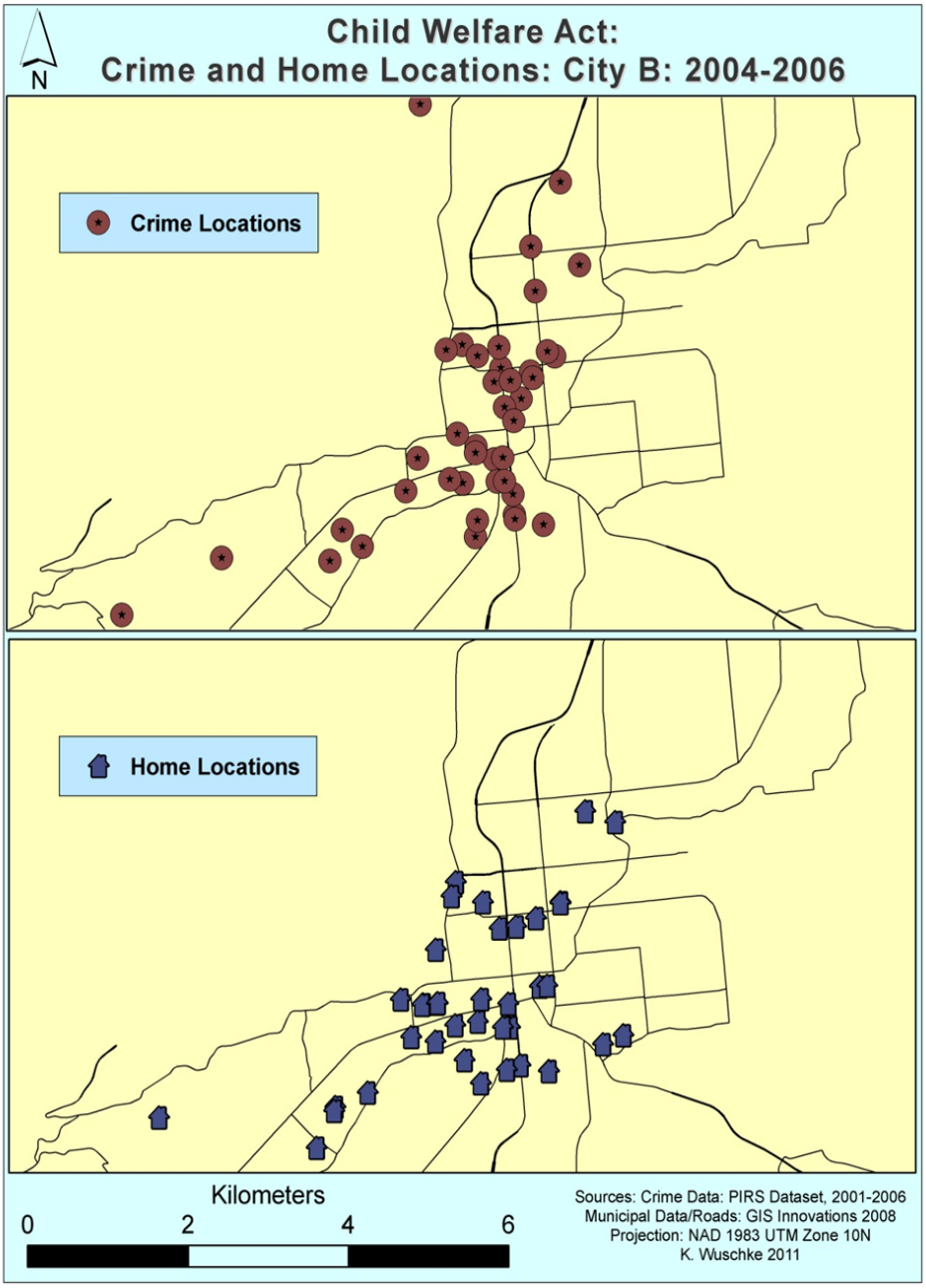
Analysis of the three example cities demonstrated that the police contacts appeared to cluster in entertainment districts or low-income housing near entertainment areas and generally not within residential areas (Figures 5.2 and 5.3). The northern detachment, City C, had the highest frequency of police contacts in one location, with 17 calls regarding the Child Welfare Act (Figure 5.4).

Figure 5.2. Crime and Home Locations in City A for Police Calls Regarding the Child Welfare Act.



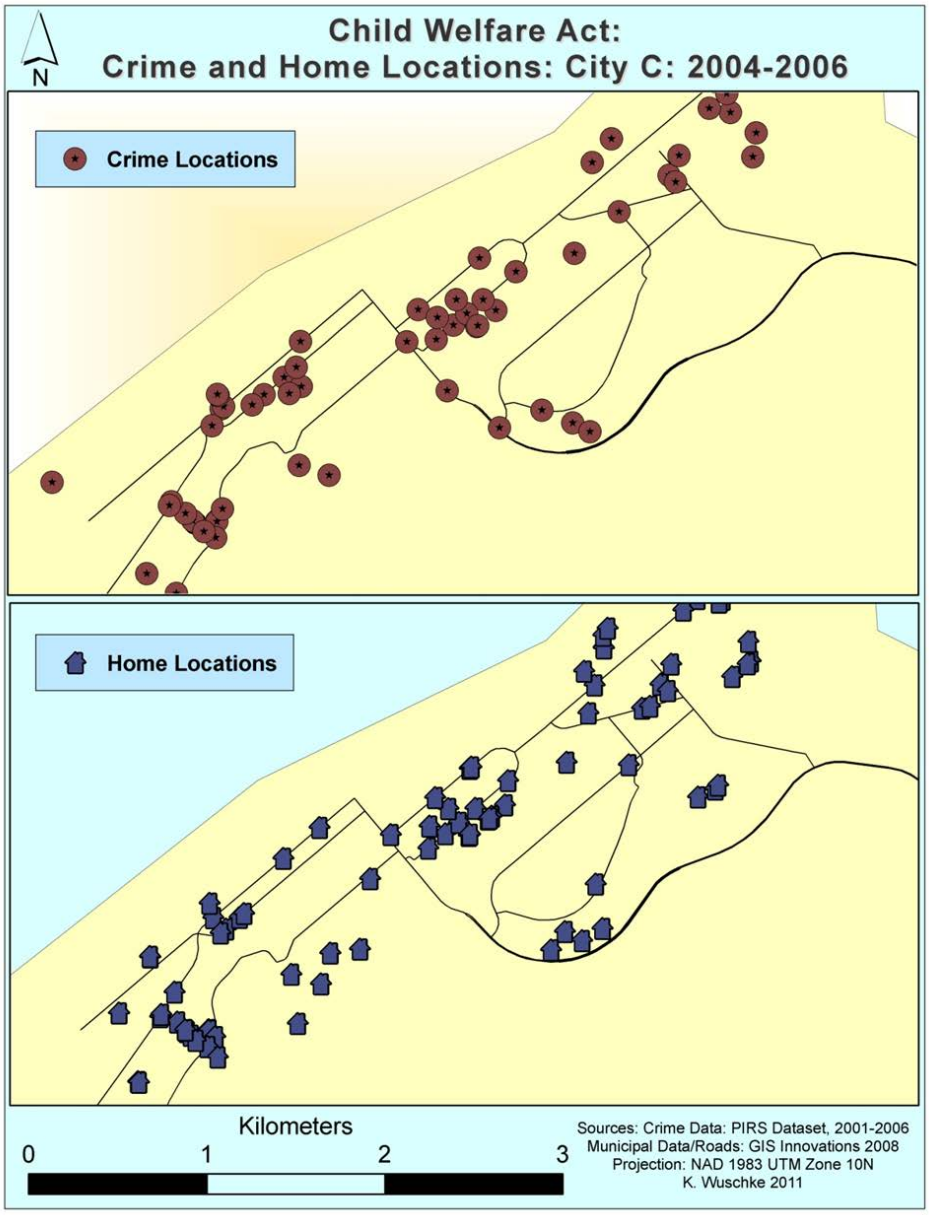
Note. Wuschke, 2011; used with permission.

Figure 5.3. Crime and Home Locations in City B for Police Calls Regarding the Child Welfare Act.



Note. Wuschke, 2011; used with permission.

Figure 5.4. Crime and Home Locations in City C for Police Calls Regarding the Child Welfare Act.



Note. Wuschke, 2011; used with permission.

In this chapter, I explored risk and protective factors for FASD and how their manipulation can lead to better prevention and treatment initiatives. I discussed current screening tools and diagnostic criteria for high risk women. I highlighted general attitudes and concerns of media campaigns and legal implications aimed at "the drinking mother". Exemplar initiatives aimed at reducing or eliminating maternal drinking at the

secondary level were provided. In addition, I summarized the common themes and most promising practices from the current literature. I concluded this chapter with an examination of the characteristics of a highrisk population.

Chapter 6.

Discussion: Primary Prevention Level

This chapter will focus on the last of the three prevention levels, the primary prevention level. At this level, the goal of an intervention is to modify those environmental conditions that increase the possibility of a phenomenon, which, in this case, is maternal drinking. Sometimes policy initiatives or interventions may appear to be driven by a "knee jerk reaction" to the prevalence of a problem, but in the case of FASD, understanding the true nature of the problem as well as acknowledging the challenges, is vital.

A primary concern at this level of prevention is not only the nature of the phenomenon itself, but also how its prevalence is determined. To this end, this chapter will begin with an exploratory review of the prevalence of FASD within the literature. The terms *incidence* and *prevalence* and issues surrounding their use will be discussed. In addition to a close look at these two concepts, I will examine how the characteristics and diagnostic criteria affect the reliability of these rates. A review of Canadian prevalence research will describe the methods, samples, and limitations of each study. Next, I emphasize the construction and prevalence of women's drinking as well as the construction of risk and disapproval of women's drinking.

Following that, I provide a summary of exemplar approaches and programs aimed at reducing or eliminating maternal drinking at the primary prevention level. Most of these initiatives are in the fields of education and law.

I conclude this chapter with a demonstration of the disjuncture between prevention initiatives and intended outcomes. For example, an illustration of accessible medical facility locations versus police contacts with intoxicated persons needing medical facilities demonstrates the clear need for evidence-based strategies.

“Prevalence Issues”

In order to develop meaningful policy initiatives, a clear understanding of not only the nature, but also the extent of FASD is vital. There appear to be inconsistencies in the discussion of the prevalence of FASD in the literature, and I hope to resolve some of those inconsistencies. Establishing the prevalence of FASD categories has been a difficult challenge since 1973 when Jones and colleagues described the first FAS cases. I first define *incidence* and *prevalence*, present existing prevalence data on FAS and the other alcohol-related effects. I then outline the characteristics and diagnosis of FASD and highlight the common approaches to determining prevalence rates.

Prevalence is generally used to describe the frequency of occurrence or presence of any one of the disorders along the FASD spectrum among a study population at all time periods during one life-time (May & Gossage, 2001). Some researchers use the term *incidence* to describe births diagnosed with FAS each year and use the term *prevalence* to indicate the rate of FAS cases within age categories beyond birth or the first year (Abel, 1995; Abel & Sokol, 1987, 1991). These definitions have been used to be consistent with epidemiology studies where *incidence* means *new cases occurring within a period of time* (number per 1,000 live births), whereas *prevalence* means *all new and existing cases during a particular time frame* (number per 1,000 people) (May & Gossage, 2001). In addition, the terms *incidence* and *prevalence* are an attempt to be more coherent with gestational considerations that are important to the study of birth defects, including FASD.

Among the other challenges in defining the prevalence of the FASD phenomena is determining what “period of time” or “time frame” will be used. For example, theoretically, a fetus can have FAS for up to 7 months prior to birth, raising the question: When is FAS considered to be a new case? This question is further complicated because frequent spontaneous abortions occur among alcohol-using women; therefore the prevalence of FAS during certain months of pregnancy may actually be much higher than the number of FAS cases recorded at birth (May & Gossage, 2001). Due to the ambiguity during this time of pregnancy and the variety of difficulties it poses, the term *prevalence* is used typically in the literature for all age groups after birth. Therefore, the term *birth prevalence* is used rather than the term *incidence* which is used for the onset of new cases for most other morbid conditions (May & Gossage, 2001). FAS, ARBD,

and ARND are conditions that generally persist throughout an individual's life; hence *prevalence* is used to describe the existence of these conditions among all age groups. Conversely some researchers do not distinguish between incidence and prevalence. Sampson et al. (1997) state that "incidence requires two key pieces of information: (1) a well-defined population to be studied over a given period, and (2) stated criteria used to define a new case of the condition" (p. 319).

Regardless of the terminology used, the above mentioned criteria for obtaining accurate estimates of prevalence pose special problems for FASD. Some of the difficulties include defining the appropriate outcome state and estimating prevalence once a definition of the outcome has been established (Sampson et al., 1997).

Sampson et al. (1997) raise the question For a given specific population and period, what is the group at risk for the condition? Is it all conceptuses, all clinically recognized pregnancies, all births of viable gestational age, or all live-born infants? (Sampson et al., 1997). Although the latter is the only one that provides a reasonable quantifiable basis, one could argue for any one of the conceptuses conditions.

Classification Considerations

Once the terminology and the diagnostic criteria have been established, a protocol for classifying cases needs to be adopted and then the question, How are the cases ascertained?, arises. Generally, ascertainment from registries is inadequate, especially when the diagnosis is difficult or stigmatizing, as is true for FASD (Sampson et al., 1997). Due to the logistical challenges of conducting clinical examinations, a population may be screened first for maternal alcohol use to eliminate low-risk infants for FAS (Streissguth, 1976).

Within the prevalence research, there has not been a single case where an individual has been diagnosed with FAS and has been an "unexposed" child. However, in a few instances, a sample of "unexposed" children may be drawn to compare to the "exposed" children to permit examiners to be blinded to exposure status (Hanson, Streissguth, & Smith, 1978). Therefore, the most representative sample would be the

result of the examination of an entire cohort rather than case-control studies or registries (Sampson et al., 1997).

Another issue that arises is when are cases ascertained? The timing of ascertainment affects the estimated prevalence of FAS as it does for many other syndromes (Sampson et al., 1997). Birth is an opportune time to make a diagnosis of FAS; however, only the most severely affected infants are likely to be identified at this time from the visible characteristics (Darby, Streissguth, & Smith, 1981). If children are diagnosed after birth, the criteria for assessment in adolescence or adulthood will change, owing to changes in facial morphology associated with puberty (Spohr, Willms, & Steinhausen, 1994; Streissguth, Clarren, & Jones, 1985; Streissguth et al., 1991). The most convenient and accurate time to establish a diagnosis is between 8 months and 8 years of age because the developmental changes have been well documented for this time frame (Streissguth et al., 1985).

Besides challenges in determining the age at which FASD can be reliably diagnosed, there are challenges with accurately measuring the phenomenon, by way of prevalence rates. Typically, in epidemiological studies, researchers use three main approaches to study the prevalence and patterns of occurrence of FAS, ARBD, and ARND: passive systems, clinic-based studies, and active case ascertainment approaches. A summary of these methods and key findings, strengths, and weaknesses associated with each approach are found below in Table 6.1.

Table 6.1. Summary of Three Main Approaches to Study the Prevalence of FASD.

Description	Advantages	Disadvantages
<u>Passive Surveillance Systems</u> Uses existing record collections for a particular geographical catchment, captured study. Researchers must first establish the criteria for defining a diagnosis of FAS, ARBD, or ARND, then teams of reviewers look for documented or probable cases in a particular time frame. Three types of records are generally reviewed: birth certificates, special registries for children with developmental	Efficiently utilize existing health care systems, programs and records already funded by other sources. Relatively inexpensive and easier to undertake than other research methods. Uses multiple types of records to identify as many alcohol-related anomalies as possible (capture-recapture methods). Relatively easy to conduct.	FAS, ARBD, and ARND are complex, involving multiple indicators of physiology, development, and behaviour, many of which are not obvious at all or are at least more difficult to identify at particular ages (Little et al., 1990; Clarren et al., 2001). Difficult to diagnose at birth (May et al., 2001). Generally, depend on the diagnoses of many hundreds of non-specialist physicians,

Description	Advantages	Disadvantages
disabilities or birth defects, and/or medical charts of hospital and physicians (May & Gossage, 2001).		educators, and other service provides (who may miss the FAS symptoms because of the circumstances of examination or the age at which the child is presented), lack the rigor and consistency of diagnoses that characterize other systems. The method depends on a variety of registries for complete and consistent records; therefore, vulnerable to the many contingencies that affect the quality of data in institutions where these data are collected (May & Gossage, 2001).
<u>Clinic-based Studies Systems</u> Consistent design and rigorous methodology that can control for many of the problems inherent in the passive methods. Generally conducted in prenatal clinics. Collection of information from pregnant woman includes diets, jobs, social interactions, psychological health, and alcohol, tobacco and other drug use using standard screening instruments and specimen samples. Pregnant women are screened for alcohol use in the prenatal period and the characteristics of their children at birth and/or shortly thereafter are monitored.	Maternal history data available. Control groups are easy to obtain, since all consenting women in the clinics are screened. Opportunity to study large numbers. Researchers are generally able to examine the infants at birth and match the maternal behaviours with the pregnancy outcomes. More control and rigor (May & Gossage, 2001).	Subjects are self-selected; therefore the women who are highest risk for FAS offspring do not regularly attend prenatal clinics and would not be included. Usually occur at publicly funded hospitals and clinics where disadvantaged populations predominate (May & Gossage, 2001). May over-represent the prevalence of FAS and the characteristics of these selected populations and under-represent middle- and upper class populations. Since FAS is not most accurately diagnosed at birth, but between the ages of 3 and 12 years, studies may also underestimate the prevalence of FAS in the population studied (Stratton et al., 1990; Clarren et al., 2001).
<u>Active Case Ascertainment Methods</u> Focuses on large populations in particular geographical or	The primary focus is on finding children with FAS at	This method is very labor intensive, time consuming, and

Description	Advantages	Disadvantages
catchment areas, such as schools, towns, and Native reservations. Are unique because they actively seek, find and recruit children who may be affected by FASD within the population under study. Once researchers set the criteria for referral to clinical examination and testing, and establish a referral network and referral procedures, clinical specialists examine possible cases and assess the physical growth and development, dysmorphology, and psychosocial characteristics of the children for a final diagnosis (May & Gossage, 2001). Maternal information may also be available through interviews or health records.	appropriate ages for accurate diagnosis by clinical specialists. Active, effective, and comprehensive outreach in a large general population is most likely to uncover children exposed prenatally to alcohol. By studying entire communities or populations, this method can eliminate much selectivity and generally ensure wide representation (May & Gossage, 2001).	costly (Stratton et al., 1996). The outreach process involves gaining permission to access a community for study, training people to recognize symptoms and referring children suspected of having FAS, locating and securing permission for maternal and child subjects, hiring specialists for the clinical assessments, and holding special "developmental clinics" that may require 2 to 3 hours to completely diagnose a single child (May & Gossage, 2001). Active case ascertainment requires cooperation from many non-researchers in the study population. If a vital community constituency does not support a study, case finding may be incomplete or selective, resulting in under-representation of the prevalence or a skewed understanding of the true characteristics of the problem. Access to particular populations may be selective, and frequently only high risk populations have been studied using these methods; therefore prevalence of FASD may be overestimated (May & Gossage, 2001).

Although of the three approaches described above, the passive methods are the least expensive and time-consuming, the majority of FASD studies in the United States have used clinic- or record-based systems (Chavez, Cordero, & Becerra, 1988; Sampson et al., 1997). These methods are believed to be superior for assessing maternal alcohol consumption (Warren et al., 2001). However, it has been noted that with clinic- or record-based systems, there is an increased likelihood of underreporting the extent and specific characteristics of a problem (in this case, FASD) in the population (Leversha & Marks, 1995).

Conversely, many researchers believe that without active case ascertainment, many alcohol-exposed children are neither detected nor referred for a diagnosis (Abel 1995; Abel & Sokol, 1987; Little et al., 1990; May & Gossage, 2002). Typically, active case ascertainment studies seek referrals of all children who may have been prenatally exposed to alcohol within particular cohorts of specific populations. Theoretically, the active case ascertainment studies are the most expensive and logistically challenging but have been considered the least affected by the selectivity in the samples (Warren et al., 2001). This method is potentially the most accurate because of the strict diagnostic criteria that are applied consistently to children whose ages (3 to 12) are most relevant to accurate assessment (Warren et al., 2001).

One of the limitations with active case ascertainment studies of FASD cases is that if they are population-based, the cases tend to have a defined population identified and accessed through outreach programs (Stratton et al., 1996). These populations tend to be predominantly minority and low-socioeconomic-status (SES) communities in the United States and South Africa (May et al., 1983). Whereas most population-based studies have used active referral systems, South Africa and Italy have utilized an in-school screening of first-grade children which appears to be successful (May et al., 2000; Viljoen, Croxford, Gossge, Kodituwakku, & May, 2002).

In general, some of the variation in prevalence rates reflects the different patterns of alcohol abuse in the different study locations (Williams, Odaibo, & McGee, 1990). However, there are also several methodological problems affecting the determination of FASD prevalence rates. For example, studies that rely solely on birth records are likely to underestimate rates because the facial features and central nervous system characteristic of FAS are often not as apparent until children are older (Williams et al., 1990). In addition, studies that follow pregnant mothers tend to underestimate rates because women who are at greatest risk for FAS babies often do not receive prenatal care (Sokol, Miller, & Reed, 1980).

Prevalence studies that are based on comprehensive assessments of all children in one specific location tend to produce higher rates because they have been specifically chosen because FAS is expected to occur there more often (Robinson, Conroy, & Conroy, 1987). In addition, some studies have combined the assessment of FAS with a diagnosis of FAE, which is considerably more common and has more ambiguous criteria

(Asante & Nelm-Matzke, 1985). Finally, studies which base their rates entirely on children who are referred for assessment may miss those children undetected by referral agents and those that are mildly affected (Asante & Nelm-Matzke, 1985; May et al., 1983). In summary, despite the increased attention it has received in the last few decades, FASD diagnosis continues to be challenging and inadequate using the current methodologies (Motz, Leslie, Pepler, Moore, & Freeman, 2006).

Prevalence of FAS and FASD

In general, estimates of FAS birth prevalence differ between countries, between ethnic groups within a country; and over time (May & Gossage, 2001). In the United States, for example, the prevalence of FAS has been reported as 1 to 3 per 1,000 live births, with the FASD rate being 9.1 per 1,000 live births (Sampson et al., 1997; Sokol & Clarren, 1989).

In Canada, there is a lack of national statistics on FASD rates, although many isolated populations have been examined. Robinson et al. (1987) determined that the fetal alcohol syndrome (FAS) prevalence was 190 per 1000 live births in an Aboriginal community in British Columbia. Square (1997) estimated the prevalence of FAS and partial FAS to be 55 to 101 per 1,000 births in a First Nations community in Manitoba, and a prevalence rate of 7.2 per 1,000 live births for northeastern Manitoba (Williams et al., 1999). Research by Asante and Nelms-Matzke (1985) determined 46 per 1,000 Native Canadian youth in the Yukon have FAS or related effects and 25 per 1000 in northern British Columbia. A prevalence for FAS of 0.589 per 1000 live births was determined from referrals to a diagnostic clinic in Saskatchewan from 1988 to 1992 (Habbick, Nanson, Snyder, Casey, & Schulman, 1996). Table 6.2 is a compilation of Canadian research regarding the prevalence of FASD and the issues with each study.

In addition, for isolated populations, very specific samples have been analyzed for FAS prevalence. For example, the Inpatient Assessment Unit of Youth Forensic Psychiatric Services in Burnaby, B.C., documented 23.3 % (of the 287 youth) having an alcohol-related diagnosis with 1.0 % FAS and 22.3 % fetal alcohol effects (FAE) (Fast et al., 1999).

In general, the major limitation in determining prevalence of such selected populations is that results can not be generalized to other communities or to the Canadian population in general. It appears that most population-based studies of FAS were carried out in predominantly minority and low-socioeconomic-status communities.

Table 6.2. Summary of Canadian Studies of FASD Prevalence.

Source	Population/Method	Prevalence of FASD	Limitation
Robinson, Conroy, & Conroy (1987)	Aboriginal community in B.C. Established criteria for diagnosis.[52] Three procedures included an interview with mothers, educational screening consisted of a school learning profile, and a medical examination included measurements of height, weight and head circumference, hearing, and vision assessment.	FAS/FAE - 190 per 1,000 children aged 18 years or less	Sample size 116, with only 54 with known prenatal alcohol exposure. Noted limitations including difficulty in confirmation of maternal alcohol use and subjectivity of craniofacial characteristics. Possibility of underdiagnosis. Elevated death rate among infants with FAS/FAE reduces the number of live affected children. A unique, high risk population makes these data impossible to compare to communities with lower drinking levels.
Square (1997)	First Nation community in Manitoba	FAS/FAE 55 -101 per 1,000 live births	Medical records of 179 families. No standardized criteria, used clinical-based records.

[52] Minimal criteria for diagnosis included history of maternal alcohol abuse or FAS in a sibling, prenatal or postnatal growth retardation (height and weight below the 10th percentile when corrected for gestational age), central nervous system dysfunction and characteristic craniofacial abnormalities, including at least two of the following: head circumference below the third percentile, short palpebral fissures and poorly developed philtrum, thin upper lip and flattening of the maxillary area (Rosett, 1980).

Source	Population/Method	Prevalence of FASD	Limitation
Williams, Obaido, & McGee (1999)	Northeastern Manitoba Birth records were screened with selected criteria. Cases were then eliminated if follow-up records indicated the child was not developmentally delayed or no longer had the small head or body size identified at birth. Cases still meeting the criteria were personally examined.	7.2 per 1,000 live births (FAS)	Sample size 745. Because only 46% of the high risk cases were personally examined, prevalence could be as high as 14.8/1,000. Only 1/5 FAS cases had been identified prior to the study.
Asante & Nelms-Matzke (1985)	British Columbia and Yukon children. Population-based study. Native and non-Natives screened using outreach in communities with comprehensive health systems.	1.4/1000 FAS among total population in northwestern B.C. 2.0/1000 FAE, 3.4/1000 total ARBD; whereas 25.0/1000 ARBD in Natives only. Yukon – 6.5/1000 FAS among total population, 5.6/1000 FAE, 12.1 total ARBD; whereas 46.0/1000 ARBD in Natives only.	Selected populations can't generalize to other Canadian communities.
Habbick, Nanson, Snyder, Casey, & Schulman (1996)	Saskatchewan. Standardized criteria for diagnosis.	FAS - 0.5/1000 in 1973-1977; 0.6/1000 in 1988-1992. No evidence of the prevalence declining.	207 cases Under-diagnosed due to failure to diagnose, lack of awareness. Could not differentiate rates between registered Aboriginal and non-registered Aboriginal.
Fast, Conroy, & Loock (1999)	Impact Assessment Unit of Youth Forensic Psychiatric Services in Burnaby, BC. Standardized assessment and diagnosis criteria including medical, psychological, psychiatric, and social work assessments.	1% had FAS while 22.3% had alcohol-related diagnosis (18.1% FAE, 4.2% ARND)	Sample size of 287. (67 were affected children). Lack of diagnosis (only 3 diagnosed before being remanded). Difficulties for inexperienced physicians making the diagnosis. Physical features change and there are more problems establishing a confirmed prenatal alcohol history. By adolescence, the opportunity for successful preventive interventions has diminished.

Source	Population/Method	Prevalence of FASD	Limitation
Smith, Sandor, MacLeod, Tredwell, Wood, & Newman (1981)	Patients at the Health Centre for Children or at the Children's Hospital in Vancouver. Selection based on history of heavy maternal alcoholic consumption during pregnancy with clinical findings in the child of characteristic facial appearance.	10.9/1 ratio of Natives with FAS to Caucasians with FAS	Sample size of 76 individuals (69 of whom were of Native ancestry) in the Yukon territory and British Columbia Ages ranged from birth to 18 years, 43 males and 33 females. Seven patients were of Caucasian descent, with the remainder being offspring of North American Indian mothers and fathers of Native Indian or Caucasian ancestry.
Wong (1983)	Surveillance registry with B.C. Ministry of Health	0.25/1000 for non-Aboriginals and 4.7/1000 for Aboriginals	Cited frequently but difficulty obtaining original surveillance data.
Burd (2003)	Survey of Canadian correctional facilities.	0.087 per 1,000.	Below estimated rate of FAS or FASD in Canadian population. Individuals are not being identified in the criminal justice system. Original report not available - only summarized in presentation.
McPherson & Chudley (2007)	Correctional population.	10 times greater incidence of FASD in the correctional population than in the general population. Approximately 20% of incarcerated people have FASD.	Size of sample was 100. Statistics are not quite complete and are difficult to substantiate

In addition, several reports suggested that FASD is more common in these specialized populations, such as correctional facilities and Aboriginal communities, than in the general public (Boland, Burrill, Duwyn, & Karp, 1998). These directed studies may utilize better diagnostic tools, superior expertise in diagnosing FAS, as well as specifically looking for FAS and related effects, which may result in an over-diagnosis in these selected populations. Conversely, prevalence rates that are determined by case files and/or general medical records may not include a diagnosis of FAS or related effects; therefore underestimating the rate within a population.

The unreliability of this determinant of the presence of FAS continues to be the country or the specific population in which the study is conducted (Abel & Sokol, 1991).

Differences in some of the critical features that go into making a diagnosis can also affect incidence rates, especially if based on some ethnic facial feature like a depressed nasal bridge or epicanthic folds that have normal variation within a particular ethnic group (Abel, 1989). This variation may result in a higher number of cases of FAS diagnosed in one population than in another. For example, there are no group norms for a Native Inuit population in Saskatchewan; therefore, estimation of growth retardation is virtually impossible, and the presence of epicanthic folds and a concave depression of the nasal bridge between the eyes is very common (Abel 1995). Because of the lack of baseline data, an Aboriginal child with unusual facial features whose mother reportedly drank during pregnancy automatically receives a diagnosis of FAS by a primary care physician (Abel, 1995). However, some researchers believe that the characteristic facial features of the child affected by FAS would be easily identifiable with proper training and familiarity with the disorder. In which case, misattribution would be a less likely explanation for the higher incidence rates in future studies, where the diagnosis would be by a dysmorphologist or other trained investigator (Abel, Martier, Kruger, Ager, & Sokol, 1993).

In conclusion, researchers, as well as policy makers acknowledge the challenges with determining the prevalence of individuals affected by FASD. However, everyone agrees that a baseline for FASD prevalence needs to be established before true evaluations of treatment or interventions can be conducted. The consensus is that diagnostic criteria, in addition to standardized methodologies, will greatly improve the accuracy in prevalence rates and, hence, assist in efforts to break the alcohol and FASD cycle.

Construction and Prevalence of Women Drinking

FASD is the result of maternal drinking; therefore, the prevalence of drinking within the population of “women of child-bearing years” needs to be addressed. Recently there has been increased attention in Canada as well as in global health agendas regarding substance use by girls and young women and the adverse social and health consequences of heavy drinking. The concern is mainly alcohol, which is the most common substance used by women, and consumption rates seem to be steadily increasing (Adlaf, Begin, & Sawka, 2005).

Research indicates that 76.8% of Canadian women reported drinking within the last year (CCSA, 2004). There appear to be concerns about some subgroups of women, particularly about 10% of women 15 to 24 years old engaged in heavy weekly drinking. Also, there seems to be an increase in high-income women who are light frequent drinkers[53] (39%) whereas, 9.3% of the lowest-income women were heavy frequent drinkers (Ahmad, Poole, & Dell, 2007). Women who drank, regardless of amount of drinking reported a range of life problems including violence and trauma, poverty, homelessness, mental health issues, and stress (Logan, Walker, Cole, & Leukefeld, 2003; Parkes, Poole, Salmon, Greaves, &Urquhart, 2008).

In addition to FASD, there are a number of other health risks for women who drink heavily including alcohol-related liver disease, hypertension, osteoporosis, brain shrinkage, and impairment and gastric ulcers (NIAAA, 2004; NIAAA, 2003). Heavy alcohol consumption can also result in ovarian shrinking or abnormal function, endometriosis, infertility, sexual dysfunction, and increased risk of breast cancer (Chen, Willet, Rosener, & Coldtiz, 2005; Watkins & Chovanec, 2006).

Although the consequences of heavy alcohol consumption are well known, a large number of women continue to drink, particularly pregnant women and "those who might become pregnant".[54] Studies have indicated that anywhere from 10 to 14% of pregnant women have consumed alcohol during their last pregnancy, and approximately 2% engaged in binge drinking (defined as five or more drinks on one occasion) (Statistics Canada, 2002). As well, about 12% of women who thought they might be pregnant consumed alcohol (Dell & Roberts, 2006). So why do these women continue to drink? And why do current policy initiatives to reduce or eliminate maternal drinking continue to fail?

[53] High-income women are assumed to have an education and ability to understand the consequences of FASD; therefore 39% is a substantial amount of women who drink 3 "standard drinks" on any one day.

[54] For example, those individuals who are sexually active with opposite sex partners and not using birth control.

Construction of Risk and Disapproval of Women's Drinking

The successful development of policy and programs is dependent on the social construction of alcohol use and associated risks, as well as on how these risks are communicated to the public (Hansen & Gunter, 2007). In countries such as the United States, the construction of risk for FASD has been medicalized,[55] hence ignoring the social and structural factors influencing women's drinking. More specifically, maternal drinking has been presented as a moral or legal issue, related to popular beliefs about motherhood, addiction, and the fetus (Armstrong, 2003; Golden, 2005). Therefore, the interpretation of the FASD risk and the associated policy developments seem to be influenced more by the social climate than existing knowledge (Kaskutas, 1995).

In addition, policy initiatives reference the social construction of "mothering" and its influence on the "FASD problem". Women are chastised for not conforming to the ideologies of "good-mothering"[56] (Salmon, 2010). It is this "mothering" discourse that serves as a means for articulating women's roles and welfare as a citizen (Salmon, 2004). Policy initiatives, such as maternal education campaigns, focus on this discourse and reiterate "these obligations, emphasising women's responsibilities to have a 'healthy pregnancy' and a 'healthy baby' by avoiding alcohol, tobacco and other drugs" (Salmon, 2010, pp. 3-4).

Historically, contextual factors influenced the interpretation of risk (of heavy alcohol consumption) and hence controlled the direction of FASD research and policy initiatives. Malbin (2007) describes the major factors contributing to women alcoholics including women's role in society, images of motherhood, double standards, and shame. Some researchers and commentators have pointed out that how society defines women's roles, particularly as mothers, has an effect both on women's alcoholism and policy initiatives. It is this social disapproval of women's alcohol use that has resulted in

[55] The term *medicalized* is used in the sense that the symptoms get treated but the problem is not dealt with.

[56] A "good" mother is perceived as being self-sacrificing, self-disciplined, morally flawless, and capable of meeting the needs of her family without assistance from the state (Anderson, 2000; Smith, 1999).

employment of coercive strategies, including punitive measures in some regions of the United States. However, in other regions, such as Canada, there is a "strong emphasis on public health interventions and mobilization of resources in support of women with alcohol problems" (Drabble et al., 2011, p. 10). The debate remains whether FASD is a health issue or a moral failure, and, depending on the chosen stance, the outcome influences current policy and practices (Connolley-Ahern & Broadway, 2008).

To reiterate, in order for FASD policy initiatives to be successful, the social, political, and historical context must be understood (Salmon, 2010). Although FASD prevention can provide opportunities for understanding the importance of each community's unique culture and spirit, it is a condition unmatched in its complexity as both a public health concern and an expression of "discrimination"[57] (Salmon, 2010). Because of the relatively new acknowledgement of the intricacy of the individual and social conditions affecting the individual, policy initiatives are moving in a more strategic, women-centred, culturally-based direction (Salmon, 2010).

Summary of Approaches and Programs: Reducing or Eliminating Maternal Drinking

The strategies and approaches associated with the primary level of prevention fall mainly into three categories: education, law, and new directions. Many of these are broad-based strategies, often referred to as *universal prevention*, that inform the public about the risks of alcohol use during pregnancy. These initiatives can include health advisories, public service announcements, and school curricula. They can be as simple as health articles and brochures distributed through a variety of outlets or warning labels about the dangers of drinking while pregnant (Nesbit, Philpott, Jeffrey, & Cahill, n.d., p. 157).

[57] Discrimination based on "gendered and racialised conditions of disenfranchisement and abandonment" (Salmon, 2010, p. 10).

Although some would argue that it could be interpreted as belonging to the secondary prevention level, I have placed the *selective prevention* approach in the primary level; this level focuses on high risk populations such as areas or communities with a higher prevalence of FASD than the general population, heavier alcohol use per capita, and trans-generational drinking problems (Nesbit et al., n.d., p. 157). Regardless of the "assigned" prevention level, the interconnectedness of this kind of initiative's focus demonstrates the need for a holistic perspective that utilizes the three levels proposed in this dissertation.

As disappointment in the lack of success of media campaigns has grown, the use of social marketing has gained popularity. These awareness campaigns attempt to connect communities requiring change at the grass-roots (Basford et al., 2004). For example, there have been a number of media campaigns where the motto included key phrases such as "reduce driving after drinking", "safe sex behaviours", and, more recently, "low risk drinking for women" (CARBC, 2008). Other campaigns strive to elicit a community response through targeted intervention strategies (Thurmeier, 2011). Rothschild (1999) determined that campaigns that have convincing messages to persuade the intended individuals but neglect to provide support services to alter the undesirable behaviours have limited success.

As well, to be successful, media campaigns seem to need to be population-specific. For example, Basford and colleagues (2004) assert that primary objectives and strategies need to be modified for each of the five following "targets:

1) Women who drink during pregnancy (Best Start, 2003).
2) Women who might be pregnant but do not realize it.
3) Adolescents (<18 years).
4) Healthcare professional.
5) Male partners of pregnant women" (pp.90-94).[58]

[58] These were taken verbatim from the text but the elaborations of each one were not included here.

Due to the diversity of these five targets and their relationship to the FASD problem, different approaches need to be implemented for each, clearly demonstrating the intricacy of the problem. If only one or two of the target initiatives are implemented, it will not result in a successful campaign.

Even though many provinces have made women's health a priority, there is still a shortage of available support services. The Vancouver Women's Hospital as well as the Maxxine Wright Community Health Centre are women-centred care facilities which operate on the belief that women are the experts in what they need or want in relation to healthcare (Penaloza & Wall, 2007). The main elements of women-centred care include respect and safety, empowerment, collaboration, communication, and harm reduction (Penaloza & Wall, 2007). The Health Determinants Perspective builds on this women-centred care and addresses social determinants of health including poverty, racism, substance use, and differential access to resources and respectfully incorporates traditional healing (Poole, 2013; Poole, Salmon, Hache, Rutman & Gammon, 2011; Salmon, 2010). The future direction of FASD policy seems to incorporate task forces, networking, and a women's health focus.

In addition, there have been a number of provincially funded services focusing on alcohol in general, and FASD specifically. One example is the Alberta Alcohol and Drug Abuse Commission, which provides information, prevention, and treatment services to those Albertans with alcohol, other drugs, and gambling problems (Nelson, 2007). Besides actual services, there has been an increase in the amount of interdisciplinary collaborations to increase FASD awareness. For example, the goals of the Women's Health Research Network task force are to connect health researchers, to identify gaps in knowledge, and to influence research, policy, and practice.[59]

Education is also one of the major areas within the primary level of prevention where preventative practices and policies can be implemented. Many educational avenues exist including prenatal visits within schools, community programs and services, and professional training for all service providers. As well, many governmental

[59] See Women's Health Research Network at www.cwhn.ca.

agencies have created innovative initiatives to prevent and reduce alcohol and drug use, as well as to increase FASD awareness.

The FASD Speakers Bureau has organized speaking engagements throughout the province of Saskatchewan. Program topics include alcohol, tobacco and other drugs, child injury prevention, maternal and infant health, parenting education, and community action programs for children (Drew, 2011). The goal is to educate everyone: including professionals, paraprofessionals, students, targeted high risk individuals, those in jails, shelters and detox centres; parents; and the general public (Drew, 2011).

Other programs target young people. For example, the Youth Action for Prevention (YAP) is made up of three unique programs to engage youth (14 - 24 years) in the primary prevention of FASD. Community-based FASD prevention, the Resource Development Project, and the Photovoice[60] Project all attempt to encourage youth to create programs and sources for their peers and to facilitate awareness and informed decision-making (Rogel & McHenry, 2011). In addition, schools are now using "coordinated community efforts" and initiating age-appropriate programs such as STARS (Start Taking Alcohol Risk Seriously) aimed at middle and junior high school youth (SAMHSA, 2004). Too Good for Drugs (TGFD) is a program designed for Kindergarten to Grade 12 students, which teaches skills that build social competence and autonomous problem solving. Family Matters is a program to reduce the prevalence of tobacco and alcohol use among children 12 to 14 years of age (SAMHSA). Project Northland focus on 6 to 8th graders in rural communities (Perry et al., 1996).

Besides educating the general public, another focus of FASD awareness should involve professionals and paraprofessionals. Surprisingly, less than 50% of health care providers discuss smoking or alcohol use with women of childbearing age (Tough, Clarke, Hicks, & Clarren, 2005). Because FASD is 100% preventable, it is imperative that physicians receive inclusive education in this field, not only to prevent exposure to

[60] Photovoice is "a participatory action research strategy by which people create and discuss photographs as a means of catalyzing personal and community change" (Wang, Yi, Tao, & Carovano, 1998, p. 75).

babies born but also in early detection of this disease, leading to interventions that can improve the quality of life of affected children (Nevin, Christopher, Nulman, Koren, & Einarson, 2002). As well, misperceptions exist among older professionals regarding warning labels, effective screening techniques, and counselling methods for women who report prenatal alcohol use (Diekman et al., 2000).

Although there is an increase in the public health message regarding maternal alcohol consumption, among the diverse group of professionals that deal with individuals affected by FASD in some manner, there seems to be a lack of understanding of the distinct requirements for working with this population. There is a need for "targeted, discipline-specific interventions" where the curricula and program design address the gaps in knowledge and take into consideration the disparity in behaviours and attitudes of high risk women and/or individuals affected by FASD (Johnson et al., 2010, p. 627).

In addition to education, many FASD policy initiatives relate to legal implications. In the Yukon and the Northwest Territories, warning labels on bottles and packaging are required by law (Caprara, Klun & Koren, 2004; Yukon Liquor Commission, 2002). The belief is that frequent exposure to warning advertisements and labels regarding alcohol consumption and pregnancy will increase awareness and dialogue (Kaskutas & Graves, 1994; Marin, 1997). However, awareness is short-lived. As soon as the campaigns end; awareness decreases (Basford et al., 2004).

In November 2012, Maple Ridge was recognized as a provincial leader in proactively addressing concerns around the misuse of alcohol when they adopted the new Business Licencing and Regulation Bylaw. This bylaw requires all licensed premises and U-Brews to post signs warning of prenatal alcohol exposure in a number of key locations including clearly visible spots where the sale or dispensing of alcohol takes place, in both the male and female washrooms of those locations where the sale of the supplies, prepackaged ingredients or equipment takes place, as well as on all menus. Besides the intended goal of this bylaw, the community hopes to draw awareness to this public concern and influence other communities around the world to adopt similar bylaws.

Another strategy is to limit alcohol consumption in general by the use of price subsidies or increased taxes (Rothschold, 1999). A few American states, including

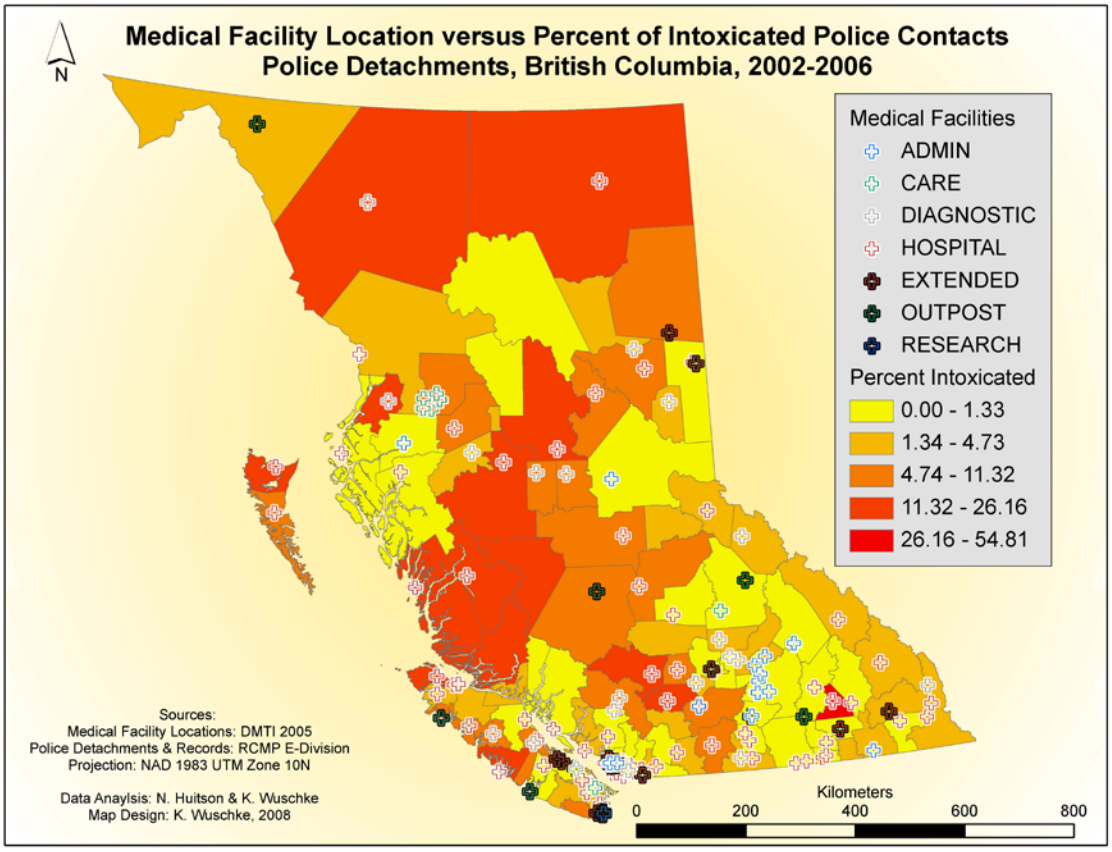
Washington, Oregon, and Rhode Island, require the mandatory distribution of "alcohol and pregnancy" brochures to all marriage license applicants (Ris, 1988). However, in Canada, there are very limited legal implications, and the main emphasis is on public health, particularly providing support and services for women who abuse alcohol.

In summary, knowledge regarding FASD and prenatal alcohol use seems to be improving but the practical applications -- services available at the community level -- are lacking. To illustrate this point, a comparison of intoxicated females[61] and medical facility locations was conducted (Figure 6.1). A number of northern communities with very limited hospital or outpost services had high percentages of police contacts with intoxicated females; therefore, I question whether the services in some of these high risk areas are adequate. As reiterated throughout this chapter, there are numerous communities with heavy alcohol use (as inferred by the percentage of police contacts with intoxicated females). These areas are high risk for alcohol-exposed infants due to the community's tolerance of alcohol use including maternal as well as trans-generational alcohol use and unaddressed social determinants such as violence and trauma, poverty, homelessness, and mental health issues.

In this chapter, I explored the prevalence of FASD and discussed the main issues regarding terminology, research methods, and current applications. I discussed prevalence, risk, and the construction of the disapproval of women's drinking. I provided a summary of initiatives aimed at reducing maternal drinking. In addition, I demonstrated the need for evidence-based strategies by illustrating the disjuncture between prevention initiatives and intended outcomes as demonstrated specifically by the juxtaposition of medical facility locations versus police contacts with intoxicated persons exercise.

[61] Data includes intoxicated females with police contact retrieved from PIRS.

Figure 6.1. Locations of Medical Services within the Province of British Columbia and the RCMP Police Detachments with Police Contacts with Intoxicated Females.



Chapter 7.

Concluding Thoughts and Recommendations

FASD can be characterized as a “wicked problem” by virtue of its being dynamic, multi-faceted, and interwoven with complex relationships. As with most social problems, FASD needs to be viewed using an integrated systems theory approach to understand its complex phenomenon. Unless that happens, the problem remains intractable and no broad, one-size-fits-all approach will be adequate. Hence, the multidisciplinary model presented in this dissertation can assist in the development of “more promising” policy and practical programs that more appropriately address the associated complexities of FASD, than those initiatives which currently exist.

This dissertation has demonstrated the dynamic relationship that exists between policy development, as informed by an integrated systems theory approach, and the creation of initiatives directed at the prevention of FASD. The unique framework presented highlighted and addressed the deficiencies that emerge from existing policies. As well “more promising” initiatives that incorporate the secondary disabilities that develop as an affected individual matures were presented. Strategic plans encompassing all levels of government were encouraged, particularly community-based services, which appear to be more successful because they are accessible to most individuals.

The Integrated Systems Model

This dissertation has presented a more complex and potentially valid policy model which stresses the multi-levelled initiatives dealing with all aspects of the FASD problem than has conventionally been presented. It was argued that initiatives need to be aimed at the individual with FASD, the high risk mother, and women of child-bearing age, in general. Therefore the prevention and treatment initiatives as derived from and

supported by evidence-based research, informs policy development. The highlights of the model and its implications for policy and programming are summarized below.

Primary Level Prevention

To reiterate, the goal of the primary level prevention of the model is to modify the environmental conditions that increase the possibility of maternal drinking. This entire model and, more specifically, this prevention level, clearly present the true nature of the problem, discuss the challenges, and demonstrate that most existing interventions and programs have been driven by a "knee jerk reaction" to the "perceived" prevalence of individuals affected by FASD. As well, I attempted to address some of the major discrepancies in the FASD literature, including debunking the use of the term *incidence*. Furthermore, with the use of the *FASD* term and all its expansion categories, the complexity of the FASD problem exponentially increases, particularly with diagnosis and prevalence determinations, and subsequent interventions.

For the most part, the terminology and the diagnostic criteria have been established but the protocol for classifying cases remains controversial. Passive surveillance systems, clinical-based studies, and active case ascertainment methods are most commonly used, but each method has major documented limitations. Subsequently, there is great variation in established prevalence rates. Most researchers and policy makers acknowledge the challenges in determining the prevalence of FASD, agree that a baseline for FASD prevalence needs to be established in order to evaluate initiatives and believe that a combination of diagnostic criteria and standardized methodologies will greatly improve the accuracy in prevalence rates.

It was also noted in the dissertation that it has recently been recognized that the prevalence of drinking in the population of women of child-bearing years needs to be better addressed. In response, Canada and global health agendas have included campaigns regarding substance use by girls and young women and the adverse social and health consequences of heavy drinking.

The social construct of alcohol use and its attendant problems were shown to be different in varying social and cultural contexts. For example, in some cultures it is seen

as a moral issue, in others, a medical one. Whatever the construct of FASD, the success of the public awareness campaigns often depend more on the social climate lens than on existing knowledge.

In addition, it was observed that the social construction of "mothering" has contributed to the "FASD problem". Recent acknowledgement of this construct and its effect on women's behaviours has altered the focus of initiatives, greatly improving individual and program success. Although there are a few exemplar approaches and programs aimed at reducing or eliminating maternal drinking, there still seems to be worrying disjuncture mainly between current practices and existing knowledge.

Secondary Level Prevention

The secondary prevention level of the model involves the early diagnosis of and interventions aimed at high risk women or mothers. Although I summarize the extensive literature on the risk factors of FASD, I also discuss the major limitations with this data, being compiled from a small number of case reviews. One issue I discuss is the lack of comprehensive examinations of risk factors, including examinations of their interactions with each other or with protective factors.

Using an integrated system theory model embedded within this tri-level model, I reviewed the risk and protective factors of FASD and explored the possible interactions between them. This structured approach is more advanced than any of the other approaches that currently exist. It encompasses an interdisciplinary perspective, and it argued, a key component is the manipulation of maternal factors which can lead to more promising preventative policies and practices. Additionally, a greater understanding of the relevant risk factors has led to new and improved initiatives and programs to address FASD. These tend to incorporate the themes of: women-centred care, gender-informed, harm reduction, service integration, and choice. All of the presented[62] initiatives appear to be innovative and evidence-driven. These policies and practices

[62] Presented within my research.

attempt to eliminate maternal drinking, to better “manage” and support individuals affected by FASD, and to encourage a healthier lifestyle in general.

Tertiary Level Prevention

The tertiary level prevention examines the individual affected by FASD and demonstrates that these individuals discussed require continuous intervention throughout their lives. Although the diagnosis of FASD has remained relatively consistent for the last four decades, there is still no objective laboratory test, and a diagnosis of FAS requires confirmation of maternal alcohol use during pregnancy and/or around the time of birth. As well, diagnosis is made on central nervous system dysfunction and facial morphology whereby ethnic populations and growth due to age further complicate FASD assessments.

However, one of the biggest issues remains the availability of diagnoses for high risk individuals and of the technology required to confirm the diagnoses: It was recommended that more funding needs to be provided to increase the number of accredited diagnostic specialists, as well to supply the equipment necessary to make proper assessments. In addition, there are a number of suggestions for reducing the barriers to access and diagnosis including the development of an international classification system, such as the International Classification of Functioning; the creation of a comprehensive framework for evaluating the organization of a coalition, such as the Internal Coalition Outcome Heirarchy; or the standardization of the Canadian Prenatal Record Forms. Only time will tell whether these attempts by the Canadian Medical Association and the government will better address the well being of both the mother and unborn child.

The research informing the model developed in this dissertation includes the constant documentation of the developmental and behavioural abnormalities of individuals with FASD since the 1990s. The major deficiencies of FASD abnormalities have been more recently linked to biological mechanisms through teratology research. Similarly, some of the common misinterpretations of normal responses in individuals with FAS and FAE have been explained and considered when developing program initiatives.

A review of the common risk factors or conditions associated with individuals affected by FASD, ARBD, and ARND provided a better understanding of the complexity of the disability and understanding which can lead to more appropriate policy and program initiatives. As well, this model clearly demonstrates the interconnectness of the health and social factors which influence an individual affected by FASD. These need to be considered when designing and implementing initiatives.

As well, the term *dysexecutive syndrome* was introduced to refer to those cognitive processes that allow for goal-oriented behaviour and which seem to be associated with the lack of rational choice that can lead to criminality. It was further demonstrated that the likelihood of secondary disabilities increases as the "unsupported" individual matures. Although there are some great examples of successful community-based policy initiatives, it appears that provincial and national FASD mandates and initiatives can be disconnected from existing knowledge.

The analysis of serious and violent offender data and legal cases provided supporting information that further substantiated the existing literature regarding the relationship between individuals affected by FASD and criminality. Current initiatives that are being implemented are now addressing the individual characteristics level, criminal versatility, and social factors that have emerged from this research and existing literature.

The examination of legal cases demonstrates the fundamental issues of individuals with FASD who are also involved in the criminal justice system. The majority of the programs and initiatives of the tertiary level provide support so the affected individual hopefully does not end up in the criminal justice system. However, if they do, their unique limitations and abilities need to be recognized, acknowledged, and then taken into consideration when a course of action is taken.

All of the above has to be transformed and operationalized into the policy environment before programs become developed. The current trend appears to be through partnerships and governmental frameworks for action (listed in Table 7.1). At first glance, these appear to be more holistic strategies that focus on the multiple levels of this paradigm. However, the rhetoric behind these strategic plans and frameworks may just be ineffective jargon. In order to implement each goal or initiative properly, an

integrative systems approach needs to be applied instead, so that the complexity of the problems and the consequences arising from them are fully addressed and all the parties involved in the "management" of the affected individual become clear. In general, governmental policies imply the use of community-based initiatives; however, actual resources needed to implement such initiatives seem to be limited.

Table 7.1. Exemplar Partnership and Governmental Frameworks.

Agency	Initiative Description
Canada Northwest FASD Partnership	www.cnfasdpartnership.ca An alliance of seven jurisdictions (BC, AB, SK, MA, Nunavut, NT, YU) Priorities are: 1. Social marketing/public awareness 2. Prevention of FASD 3. Community capacity 4. Training/Education 5. Government leadership 6. Evaluation/Research The research network has been able to: Facilitate / enhance highly productive linkages across jurisdictions, perspectives, and disciplines; develop, facilitate and foster relationships, research programs, and initiatives across the spectrum of FASD research activity; Answer high priority, underlying questions about the prevention of FASD and the diagnosis and support of those living with the disability; and inform policy, practice, and decision-making in these areas.
Alberta Government Provincial FASD 10-Year Strategic Plan: 2007-2017	www.fasd-cmc.alberta.ca Committee's mandate to develop a strategic plan in order to advise and make recommendations to government and community in order to achieve desired outcomes: in the areas of awareness and prevention, assessment and diagnosis, supports for individuals and caregivers, research and evaluation, training and education, and stakeholder engagement.
Fetal Alcohol Spectrum Disorder: Building on Strengths A Provincial Plan for British Columbia 2008-2018	www.mcf.gov.bc.ca/fasd/ Improving on the 2003-2008 Provincial Plan with Strategic Priorities for 2008-2018 1. British Columbians are aware of the risk of alcohol and substance use in pregnancy and of FASD as a lifelong disability (for each priority, it is addressed at the individual/community level, professional and service providers, policy, and research and evaluation levels). 2. All women of childbearing age and their partners and support systems have access to early support and follow-up. 3. All pregnant women and mothers experiencing substance use problems and their partners and support systems have access to focused intervention and support. 4. Children, youth, and adults living with FASD have access to timely diagnosis and assessment. 5.Children, youth, and adults living with FASD and their families and support networks have access to comprehensive and lifelong intervention and support. 6.Service systems are coherent, integrated, and coordinated and benefit from strong research and evaluation.
Public Health	www.publichealth.gc.ca/fasd

Agency	Initiative Description
Agency of Canada Fetal Alcohol Spectrum Disorder (FASD) A Framework for Action	The five broad goals: 1. Increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy. 2. Develop and increase capacity 3. Create effective national screening, diagnostic, and data reporting tools and approaches. 4. Expand knowledge base and facilitate information exchange. 5. Increase commitment and support for Action on FASD.

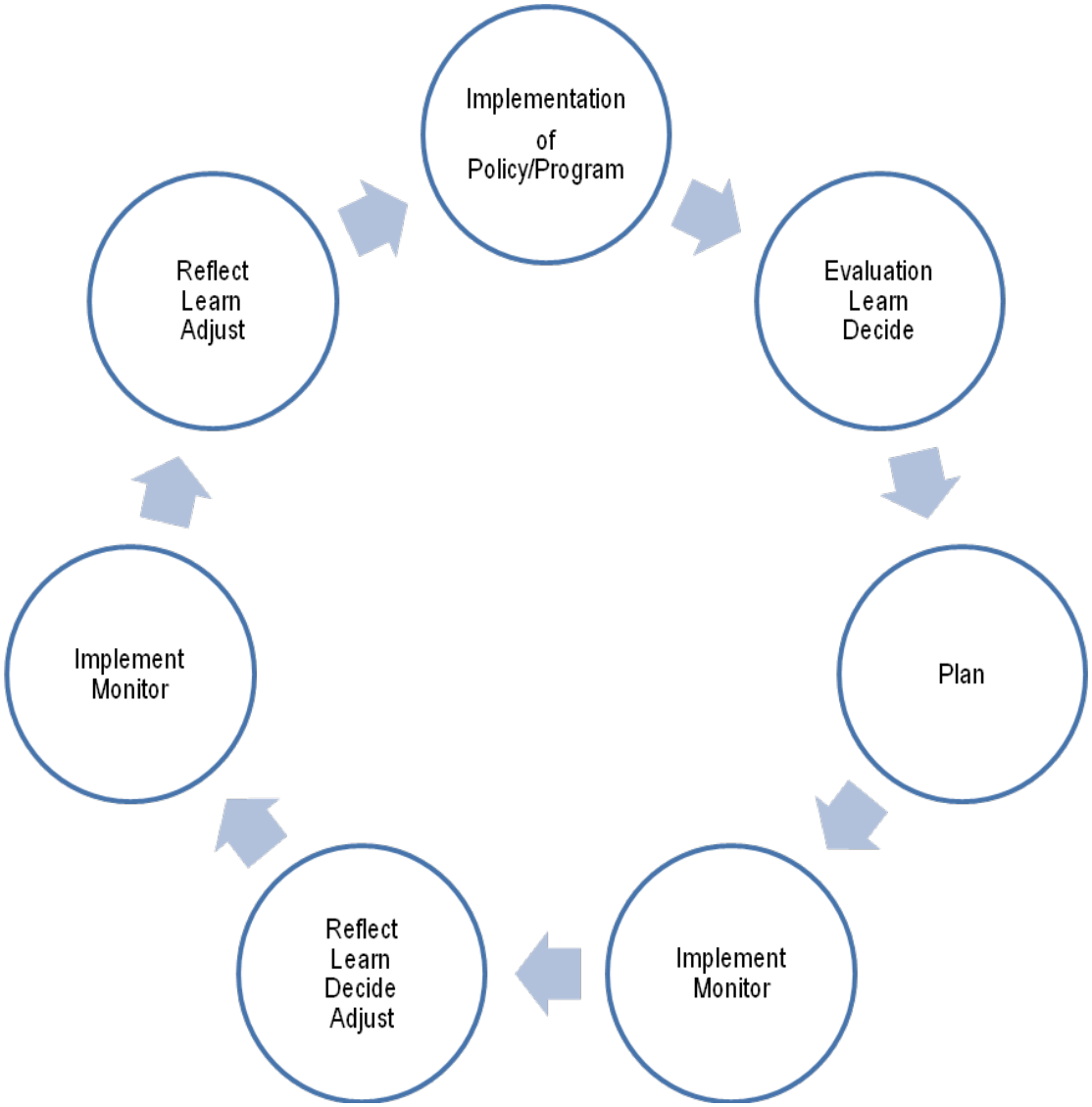
Given all these initiatives, why haven't we eliminated or significantly reduced the occurrence of FASD? Could it be said that we have conformed to the "GoodEnough Syndrome" where success is defined as "the lowest common denominator of achievement" (Chasnoff, 2011, p. 419)? I believe that the measurement of success needs to be redefined and made more specific. In the past, program initiatives have been evaluated by success or failure, measured against a fixed goal, or inspected for FASD individually (Rutman, Poole, Hubberstey, Hume, & Bibber, 2013). A new way of thinking for evaluation involves feedback loops that are an integral part of the evaluation and are not thought of as an "addendum" (Figure 7.1) (Rutman et al., 2013). As well, these feedback loops can be integrated within each of the prevention levels presented in this policy paradigm.

Since it has been shown that FASD is a "wicked problem", one that is dynamic, multi-faceted, and comprised of complex relationships, it makes sense that it would be similarly in need of a "wicked answer". A wicked answer which considers and matches those complexities in solutions derived from the comprehensive, integrated, multi-leveled prevention paradigm proposed. Along with the development of those wicked solutions, their successes and failures need to be specifically evaluated by the stakeholders. Based upon that analysis, any "impediments to change" or reform need to be identified.

By using the integrated systems model within the three prevention levels, I did highlight many exemplar initiatives (solutions), which directly related to reducing or eliminating maternal drinking, as well as better management of individuals affected by FASD. Why haven't more of these successful initiatives been adopted? I question whether it is the social atmosphere/social attitudes that surround FASD alone which limits their progress. In the end, regardless of the great strides we have made in FASD research, I continue to ask myself the question: What more can be done to link good

policy intents to reduce FASD with good programming developments and effective outcomes?

Figure 7.1. A New Way to Approach Evaluation. Modified from Rutman et al., (2013). Feedback Loop Example.



Recommendations and Future Research

Even though the gap in knowledge is lessening, there are still questions that remain unanswered. Future research needs to address these questions. With a better understanding of the minimum level of alcohol that causes harm or the exact times when

damage occurs, better implementation strategies can be employed. As well, with more concrete evidence of damage to the developing embryo, more attention can be brought to the problem, which one would hope would result in decreasing or eliminating maternal drinking.

Evaluations need to be made in order for there to be continuing improvements in diagnostic tools and criteria. But most important is the need for the availability of screening and diagnostics, if required, in high risk communities and for high risk individuals. The lack of resources and availability seems to be a reoccurring theme to be studied. In addition, the lack of acceptance that FASD is a "psychological" condition that needs appropriate designation so that services are made available is another theme for researching. Thus, it is proposed that FASD be included in the DSM, giving the condition more credibility and acknowledgement that is needed in support services and within the criminal justice system.

There have been great strides in alcohol teratology research. However, there is still no determined minimum number or definitive combination of factors which can be said to result in FASD. From the literature, it appears that FASD is a "lower socioeconomic" phenomenon. But FASD does occur in middle class populations as well, where it remains invisible and "voiceless". We need to know about these individuals and examine more closely the maternal factors that contributed to drinking during pregnancy. More importantly, we need to study those women who were known to binge drink during pregnancy but had children that were not affected by FASD. This specific population may provide clues as to more specific requirements for a FASD diagnosis and also may aid in more effective preventative initiatives.

Another need is that research globally needs to become more consistent. The current message regarding "drinking and pregnancy" is mixed. Is the inconsistency due to a lack of research in the area, a political influence in the message, or is there really a difference in adverse fetal outcomes depending on where you live?

By employing this tri-level prevention paradigm, which incorporates an integrated systems approach, a number of questions do not necessarily need to be answered before "more promising practices" emerge and can be implemented. Whether or not FASD is a social or a health issue remains a contentious discussion. Whether it is solely

a girl's or women's issue is another discussion. By aiming prevention initiatives at all three prevention levels and all facets of the problem, as indicated by the integrated systems approach, the issue will be addressed regardless of terminology used.

The collaborative approach needs further researching. Even when the "collaborative" or "community" approach is highly recommended and utilized, problems can emerge. There still may be disagreement in the definition or identification of the actual problem. Each representative of the planning group may have different goals and actions (Russell, 2011). As well, the question remains whether all of the concerned groups and coalitions of the community are included in the conversation and implementation. Does the process include consistent feedback, so strategies may be altered or adapted immediately? Due to the nature of the collaborative approach, it may be difficult to maintain and sustain forward momentum (Russell, 2011).

As stated before, there have been amazing advances in diagnostics, alcohol teratology research, and most promising initiatives, but these seem to be in isolated hubs. The isolation contributes to a lack of communication and dissemination of information, and vice versa. There needs to be a central information warehouse for an up-to-date database of current research, services, relevant legal cases, program initiatives, non-profit agencies, and support groups and so forth, so that anyone could go to one centralized location and get the information required or be directed to where it is available. In addition, those parties who have information on individuals affected by FASD (i.e., case histories)[63] should make available the information to researchers so that better-informed preventative or management initiatives can be developed.

Future Dissemination

Of the most successful venues for the dissemination of information are the various FASD conferences. The International Conference on Fetal Alcohol Spectrum

[63] With the understanding that researchers, acknowledge and respect the sensitivity of the information and will adhere to anonymity and confidentiality as per the ethics requirements of the specific institutions.

Disorder began in 2005 with approximately 150 individuals interested in addressing the FASD problem. It has evolved into two streams of focus: the International Conference with an emphasis on policy and research (Table 7.2) which had over 1100 attendees at the last conference, and the National Conference, which focuses on current issues with adolescents and adults with FASD (Table 7.3).

Table 7.2. List of International Conferences on FASD.

Date/Location	***Conference***	***Conference Title***
March 7th-10th, 2007 Victoria, B.C.	The 2nd International Conference on Fetal Alcohol Spectrum Disorder	Research, Policy and Practice Around the World
March 11th-14th, 2009 Victoria, B.C.	The 3rd International Conference on Fetal Alcohol Spectrum Disorder	Integrating Research, Policy and Promising Practice Around the World: A Catalyst for Change
March 2nd-5th, 2011 Vancouver, B.C.	4th International Conference on Fetal Alcohol Spectrum Disorder	The Power of Knowledge: Integrating Research, Policy, and Promising Practice Around the World
February 27th-March 2nd, 2013 Vancouver, B.C.	The 5th International Conference on Fetal Alcohol Spectrum Disorder	Research: Results and Relevance: Integrating Research, Policy, and Promising Practice Around the World
March 4th-7th, 2015 Vancouver, B.C.	The 6th International Conference on Fetal Alcohol Spectrum Disorder	Research: Results and Relevance: Integrating Research, Policy, and Promising Practice Around the World

Table 7.3. List of National Conferences on FASD.

Date/Location	Conference	Conference Title
April 9th-12th, 2008 Vancouver, B.C.	Third National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder	FASD and Mental Health: The Wisdom of Practice
April 15-17th, 2010 Vancouver, B.C.	Fourth National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder	Facing the Future Together: Where Do We Go From Here?
April 18-21st, 2012 Vancouver, B.C.	5th National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder	It's a Matter of Justice
April 9-12th, 2014 Vancouver, B.C.	6th National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder	Changing the Conversation

It appears that we are slowly getting the word out and moving in a positive and "global" direction, as indicated by conference titles such as "integrating research" and "promising practices around the world". As well, the government of Alberta, in conjunction with the Institute of Health Economics, introduced two new conference series: the "First International Conference on Prevention of FASD" and the "Consensus Development Conference on Legal Issues of FASD" both successfully attended in September 2013. However, I do wonder if information about these is getting out and if they are accessible to the people who need them the most.

One final note, at the individual level, regardless of all the great research, policy, and practices that have evolved, it comes down to whether the individual wants to make preventative changes. New ways need to be discovered to facilitate and encourage these changes in high risk women; hence a new avenue for me to explore. Regardless, we must continue to whittle away at the wicked problem, so hopefully, one day, the FASD enigma will be solved.

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Appendices

Appendix A.

Common Risk Factors Associated with Heavy Maternal Drinking, FAS, and ARBD/ARND.

Influential Element	Maternal Risk Factor	Source
Genetic	Alcohol metabolism and liver phenotype	May, 2013; May, 2011
Health	Older than age 25 when FAS child is born	Jacobson et al., 1994; Viljoen et al., 2002
	Already has three or more children when FAS child is born	Abel, 1990, Miller et al. 1995
	Short intervals between births of children	Abel, 1990
	Use of other drugs	Bagheri et al., 1998
	Use of tobacco	Bagheri et al., 1998; Viljoen et al. 2002
	Use of illicit substances	Abel, 1990; Niccols, 1994
	Hypoxia and free-radical damage	Abel & Hannigan, 1995
	Maternal zinc deficiency	Chambers, 2011
	Stressors including chronic disease states, such as diabetes or alcoholism, or transient stressors as in the case of acute maternal infection	Chambers, 2011
	Poor health	Abel, 1990
	Poor nutrition and diet	Abel, 1990; Bagheri et al., 1998
	Body mass (BMI) and weight of the mother	May, 2013; May, 2011
	Untreated or under-treated mental health concerns	Chudley et al., 2005
	Low pregnancy weight	Abel, 1990
	History of spontaneous abortions	Abel, 1990
	Vanishing twin phenomena	Mathelier & Karahorlu, 1999
	Limited parental care	Bagheri et al., 1998
	High gravidity and parity	May et al., 2005

Influential Element	Maternal Risk Factor	Source
	Morbidity or premature mortality from alcohol-related causes	O'Leary, 2013; Abel, 1990;
	Previous FAS child	Abel 1990; Abel & Hannigan, 1995;
Socioeconomic status (SES)	Low SES	May, 2013; May et al., 2004
	Social transience	NIAAA, 2000
	Single	Leonardson & Loudenburg, 2003
	Unemployment or marginal employment	Abel, 1990; Leonardson & Loudenburg, 2003
	Lower level of education	Sood et al., 2001
	Lower level of religiosity	May et al., 2004; Viljoen et al., 2002
	Weathering	May, 2013; May, 2011
	Aboriginal status	Niccols, 1994
	Custody and custody changes	Boland et al., 1998; Sood et al, 2001
Drinking Pattern	Early age at onset of regular drinking	NIAAA, 2000
	Frequent binge drinking (consuming five or more drinks per occasion 2 or more days per week)	May, 2013; Chudley et al., 2005; May et al., 2004; Niccols, 1994
	High blood alcohol concentration	Jacobson & Jacobson, 1999; 1994; Sood et al., 2001
	No reduction in drinking during pregnancy	Chudley et al., 2005; May et al., 2004
Psychological Profile	Low self-esteem	NIAAA, 2000
	Depression	NIAAA, 2000
	Sexual dysfunction	NIAAA, 2000
	Adverse psychosocial circumstances	Bagheri et al., 1998
Family Social Traits	Alcohol misuse in family	May et al., 2004
	Paternal drinking and drug use	May et al., 2004; Sood et al., 2001
	Tenuous marital status (cohabitation, never married,	May, 2013; May et al., 2004

Influential Element	Maternal Risk Factor	Source
	separated, or divorced)	
	Loss of children to foster or adoptive placement	NIAAA, 2000
	Abuse incidents	Chudley et al., 2005
	Poor developmental environment (stress, abuse, neglect)	Sood et al., 2001
	Greater number of alcohol-related risks	May & Gossage, 2001
Local Culture and Community	Relatively tolerant of heavy drinking	NIAAA, 2000
	Reduced access to prenatal and postnatal care and services	Sood et al., 2001
	Socially isolated	Sood et al., 2001

Appendix B.

Protective Factors Associated with Heavy Maternal Drinking, FAS, and ARBD/ARND.

Influential Element	Maternal Protective Factor	Source
Genetic	Liver isoenzyme polymorphism (alcohol dehydrogenase (ADH)) 2*2	May et al., 2004
	Alcohol dehydrogenase ADH2*3	McCarver et al., 1997
	Alcohol dehydrogenase ADH1B*3	Jacobson & Jacobson, 2007
	Susceptibility to alcohol teratogenesis	Chasnoff, 1985; Christoffel & Salafsky, 1975; Streissguth & Dehaene, 1993
Health	Low gravidity and parity	May et al., 2005
	Adequate nutrition and larger body size	May et al., 2005
	Low gravidity and parity	May et al., 2005
	Maternal folic supplement	Chambers, 2011
	Choline supplement	Chambers, 2011
Demographic	Being married and higher income	Leonardson & Loudenburg, 2003; May et al., 2005
	Full-time housewife status	Leonardson & Loudenburg, 2003
	Non-drinking male partner	May et al., 2005