Funded by the Ministry of Children and Youth Services, The Alberta Centre for Child, Family and Community Research (The Centre) is an innovative resource for evidence. The Centre develops, supports and integrates research across sectors and disciplines to provide a strong, evidence-based foundation for identifying and promoting effective public policy and service delivery to improve the well-being of children, families and communities in Alberta, Canada, and internationally.

The Centre works in conjunction with Alberta Children and Youth Services, eight other Alberta child-serving ministries, the Government of Canada and numerous other partners and collaborators to improve the well-being of children by:

• Identifying the needs for evidence;
• Supporting high priority initiatives of Children and Youth Services and the Government of Alberta;
• Supporting research capacity building;
• Providing direction to leading edge research initiatives; and
• Developing an extensive network of collaborative partnerships.

The Centre also manages The Child and Youth Data Laboratory (CYDL) Initiative that analyses linked data from nine ministries to provide a comprehensive profile of the trajectories and outcomes children and youth experience as they access multiple programs across several provincial government programs.

For additional information please visit
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Introduction
The Alberta Centre for Child, Family and Community Research (The Centre) is an innovative resource that mobilizes research evidence into policy. Because children and their families in Alberta share fundamental needs with children living elsewhere, our research has relevancy and impact that extends outside of Alberta, thus making The Centre an innovative nexus for the most important issues for children.

The Centre funds policy relevant research on Fetal Alcohol Spectrum Disorder (FASD) and other thematic areas dedicated to optimizing the well-being of children, families, and communities. The Centre’s research themes and sub themes are listed in Appendix 1. An overview of our grant opportunities are included in Appendix 2. Information on FASD, including definitions, characteristics, key facts, prevalence rates and economics are presented in Appendix 3.

The Beginning of The Centre
In 2003, Iris Evans, former Minister of Alberta Children and Youth Services approved the inaugural grant to establish The Alberta Centre for Child, Family and Community Research (The Centre). The Centre’s first priority was to support research on the prevention of Fetal Alcohol Syndrome and to build knowledge on how to improve outcomes for those affected by Fetal Alcohol Spectrum Disorder (FASD).

Initiating the FASD Research Agenda
To identify promising practices and gaps in knowledge, The Centre initiated its FASD research agenda by commissioning an International Research and Practice Inventory (2003) and two State of the Evidence Reviews on Prevention and Intervention (2004). The Reviews revealed that the research on FASD prevention and intervention was only at an early beginning stage. There was a critical gap in the number of prevention and intervention programs being developed, implemented and evaluated. The Centre released the first among many calls for research proposals to generate evidence and mobilize the results to inform important policy and practice decisions on FASD.

Building Capacity FASD Research in Alberta
The Centre continues to fund studies undertaken by Alberta scientists and build capacity for their many team members to contribute to leading edge research on FASD. These researchers include Dr. Carmen Rasmussen, Dr. John McLennan, Dr. Gail Andrew, Dr. Suzanne Tough, Dr. Mathew Hicks, Dr. Jacqueline Pei, Dr. Dorothy Badry, Dr. Robert Sutherland, Dr. Karen Benzies, Dr. Shahirose Premji, Dr. Lola Baydala and others.

The Compendium
This compendium highlights FASD research and knowledge mobilization projects funded by The Centre. Results, recommendations for service providers, policy makers, educators and considerations for future research are included in the study summaries. The compendium also acknowledges several of the Government of Alberta initiatives focused on FASD prevention, intervention, education and service provision.
Mobilizing the Knowledge on FASD

Learning Events
In October 2004, The Centre hosted the first symposium to present and discuss the findings and implications of the State of the Evidence Reviews on FASD Prevention and Intervention strategies. Several other knowledge mobilization events included a focus on FASD including:

Family Supports for Children with Disabilities, March 10, 2005
Research Showcase, October 29, 2009
Safe Communities Showcase, November 3, 2009
FASD Community of Practice, November 30, 2010

Speaker presentations are accessible for viewing and a significant number of resources and research information relevant to FASD are available at www.research4children.com

Institute of Health Economics (IHE) FASD Consensus Conference - 2009
The Centre supported the 2009 Institute of Health Economics Consensus Development Conference on FASD: Across the Lifespan. The Centre’s President and CEO, Nancy Reynolds moderated the two day event and served on the Conference Planning and Scientific Committees. The Centre’s Scientific Director, Dr. Suzanne Tough presented on the prevalence and incidence of FASD in Alberta and Canada. The IHE Consensus Development Conference on FASD: Across the Lifespan, was held October 7 – 9, 2009 in Edmonton, Alberta. This conference, with its unique and compelling “jury trial” format, examined the following questions:

- What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?
- Do we know the prevalence and incidence of FASD in different populations and can the reporting be improved?
- What are the consequences of FASD on individuals, families and society?
- How can FASD be prevented?
- What policy options could more effectively support individuals with FASD and their families across the lifespan?
- What further research into FASD is needed?

Recommendations addressing each for the key questions listed above are available in the Consensus Statement on Fetal Alcohol Spectrum Disorder (FASD) Across the Lifespan report located on the IHE website in addition to speaker presentations recorded at the conference http://www.ihe.ca

This knowledge mobilization project is based on the results from Exploring Pharmacists’ Role in FASD Awareness, Prevention and Intervention study described on page 68 of this compendium. The Centre collaborated with the Ministry of Children and Youth Services, the Alberta College of Pharmacists and the Faculty of Pharmacy at the University of Alberta to develop a survey to gauge Pharmacists’ level of interest in learning more about FASD and participating in awareness in prevention efforts.
Of the 566 respondents, 75% felt they could benefit from training in FASD awareness, treatment and patient education, and indicated willingness to distribute awareness and prevention materials to clients in their communities. More than half of respondents were interested in participating as a community resource in FASD prevention in the areas of referral, awareness and counseling.

Based on these results, The Centre is currently working with the Ministry of Health and Wellness, the Ministry of Children and Youth Services, the Alberta College of Pharmacists and the Faculty of Pharmacy at the University of Alberta to develop, deliver and evaluate evidence-based educational programs on FASD for:

- 3rd Year Pharmacy Students
- Practicing Pharmacists (Accreditation Course)
- Interdisciplinary Health Care Students working with inner city youth at the SHINE Clinic (Student Health Initiative for the Needs of Edmonton)

The educational program for the 3rd year pharmacy students will consist of a lecture and lab/workshop based approach and include a communication skills enhancement component to prepare students to engage in client education. A Researcher/Physician, Pharmacist, Social Worker and Psychologist will develop and deliver the program. Presentations will be recorded and DVDs will be created for future use.

An interdisciplinary educational course on FASD for practicing community Pharmacists will also be developed. The course will be piloted in face-to-face events with practicing community Pharmacists in Fort McMurray, Calgary and Edmonton. The final session in Edmonton will be webcast live for Pharmacists to participate through out Alberta. This session will be recorded on DVD and submitted to the Canadian Counsel on Continuing Education in Pharmacy for accreditation as a web based distance education course.

The SHINE Youth Clinic is a student-run health clinic providing a variety of free services to Edmonton’s underserved youth. The clinic is managed and staffed by University of Alberta Healthcare volunteer students and preceptors representing six disciplines; Medicine, Dentistry, Nursing, Pharmacy, Social Work, and Nutrition. Services provided include: Counseling Psychology, condom distribution, HIV, STI, Pregnancy Tests and Health Education.

An Interdisciplinary FASD educational program will be designed for SHINE Clinic workers and will include training in communication skill development and approaches to patient education for this inner city population. The program will be delivered in workshop sessions and will be recorded for future presentations.

This project is innovative as the initial literature review found no previous evidence or reference to the involvement of community Pharmacists in FASD awareness and prevention campaigns. The results of this initiative include the engagement of Pharmacists to join other health care professionals to work towards decreasing the incidence of FASD.
Alberta Government Takes Action
Addressing FASD is a priority of the Alberta Government. Since 2007, they have invested nearly $37 million for FASD programs and services (26). The government supports programs that enhance the awareness and understanding of FASD, educate women not to drink when pregnant, and support individuals and families affected by FASD (26).

Government of Alberta FASD 10 Year Strategic Plan
The Government of Alberta established the Fetal Alcohol Spectrum Disorder Cross-Ministry Committee (FASDCMC) to provide a coordinated approach for a unique made-in-Alberta framework for addressing FASD. The result is the FASD 10-Year Strategic Plan. The FASD 10-Year Strategic Plan provides an overview of the scope and impact of FASD on individuals and families in Alberta. It identifies a vision, mission statement, guiding principles and a broad framework for the coordination, planning and delivery of FASD services across Alberta in the areas of:

- Awareness and Prevention
- Assessment and Diagnosis
- Supports for Individuals and Caregivers
- Research and Evaluation
- Strategic Planning
- Training and Education
- Stakeholder Engagement

The document provides a definition for each area, and identifies target groups, desired outcomes, and gaps in services and supports. In addition, the future strategies associated with each area are highlighted and strategy leads are identified for implementing the FASD 10-Year Strategic Plan. http://www.fasd-cmc.alberta.ca

Fetal Alcohol Spectrum Disorder Cross-Ministry Committee FASD Learning Series
The FASD Learning Series offers free education opportunities tailored to meet the unique needs of individuals and family members/caregivers affected by FASD, support service providers, healthcare providers, educators, legal and justice services, and professionals in the research and evaluation field. These sessions also provide participants the opportunity to interact with the presenter during a facilitated Q&A period, and meet and share with people from all areas of the FASD field. All sessions are recorded, and available for viewing at http://www.fasd-cmc.alberta.ca

FASD Service Networks
FASD Service Networks are groups of community and government agencies who work together to promote FASD prevention and services for families and individuals.

What They Do:
- Assessment and diagnosis by a multi-disciplinary team
- Targeted prevention for those most at-risk of giving birth to a child with FASD
- Support services for Albertans affected by FASD
- Coordinate access to services
Who They Help:
- At-risk individuals and families
- Individuals suspected of having FASD and their caregivers
- Individuals diagnosed with FASD and their caregivers

What They Can Provide:
FASD Service Networks can provide coordinated access to support services to meet the needs of those living with FASD and their caregivers, which vary in each Network and may include:

- Enhanced support for at-risk women
- In-home and outreach support for children and youth whose parents have FASD
- Support for caregivers of children, youth and adults living with FASD
- Life skills programs for youth and adults living with FASD
- Assessment and diagnostic services

Through the Networks, individuals and families have an organized and centralized resource that can assist them in seeking services and programs, and provide them with new hope. For information about preventing FASD, services and supports available, visit www.fasd cmc.alberta.ca

The Canada Northwest FASD Research Network
The Canada Northwest Fetal Alcohol Spectrum Disorder Research Network (CanFASD Northwest) was established in March of 2005, through the support of the Governments of Alberta, British Columbia, Saskatchewan, Manitoba, Yukon, Northwest Territories, Nunavut, the Canadian Northwest FASD Partnership and The Centre.

CanFASD Northwest is a formally and informally connected, widely dispersed group of professionals from a range of research sciences, who are located across western and northern Canada. They are involved in the use of scientific methods in the pursuit of advancing knowledge. Teams answer questions requiring research and evaluation posed by governments, organizations, and communities.

Their website http://www.canfasd.ca/ hosts a Research Library which contains a project inventory of FASD research, programs, courses and demonstration projects underway within the Canada Northwest region.
Centre Funded FASD Research Summaries
The following section provides summaries of the findings from FASD research and knowledge mobilization projects funded by The Alberta Centre for Child, Family and Community Research. Considerations for policymakers, service providers and administrators are included. The full reports are available on The Centre’s website at www.research4children.com

Research findings and considerations are from Centre-funded research only as a means to highlight these studies and their findings. They are not reflective of all research in this area. The information contained in each report is the property of the research teams.
Fetal Alcohol Spectrum Disorder

International Research and Practice Inventory:

Focus on Prevention and Intervention

Faculty of Social Work
The University of Calgary

Dorothy Badry, MSW, RSW
Isabelle Chouinard, B.Sc., BSW

September, 2003
1. Executive Summary

A literature scan was undertaken to discover available research and resources outside of Canada in relation to Fetal Alcohol Spectrum Disorder. The primary focus of the search was in the areas of prevention and intervention. Much of the current literature emerges from the medical field. The notion that FASD is entirely preventable through abstention from alcohol during pregnancy is a common thread within the literature. The recognition of social issues such as alcoholism, poverty, oppressive social structures and systems that are distinctly related to the birth of children with FASD is not given a voice in the literature. There are underlying reasons why women drink during pregnancy and this requires further examination. Past and current research has tended to focus on the teratogenicity of alcohol and on observed disabilities in children exposed to alcohol during pregnancy. Recognition that best practices in prevention are lacking is the driving force behind some of the research projects currently under way. A review of the current literature in regards to research and activities towards prevention and intervention of FASD uncovered only a few publications. There are existing programs highlighted in this report that are currently being implemented and evaluated for success rates. Most research in this field tends to concentrate in the United States, whereas other countries appear to focus research efforts in the description of FASD and also in providing this information in support to families.

Ann Streissguth, PhD, a noted researcher in the field of FASD refers to the 5 P’s of prevention: Public Education, Professional training, Public Policy, Programs and Services, and Parent and Citizen Activism. The current efforts as it appears in the literature tend to focus on public education and professional training. Although some projects are currently being conducted to address the need for programs and services as well as public policy, there is a critical gap in the number of prevention and intervention programs being developed and implemented. In particular, most programs tend to focus on educational aspects of prevention, and programs that are supportive in nature are few.

As a source of information, the World Wide Web stands out as a primary source of knowledge regarding FASD. There are many credible organizations with websites that have done a great deal to promote solid education regarding FASD. However, it should be noted that information on the web should be scrutinized in terms of its claims of truth or knowledge regarding FASD. International sources that were found on the Internet promoted family advocacy and support and did not reveal information about ongoing research, and this is either due to lack of information, or information presented in another language. International links are documented within this report.

Health related professions have been instrumental in promoting awareness regarding FASD and clinical medical research has been critical in developing an understanding of the complexities of this disability. There is a large body of literature which offers a focus on community activities, advocacy and support networks for individuals with FASD and their caregivers. The research on prevention primarily focuses on educating birth mothers and pregnant women on the dangers of alcohol consumption during pregnancy. A great deal has been invested on advertising campaigns that recommend women who are pregnant refrain from consuming alcohol. What appears to be lacking around FASD prevention is a broader focus on the socioeconomic structures which gives rise to alcoholism and substance abuse. Literature that focuses on
intervention with women who are at risk of giving birth to children with FASD is limited. Many activities regarding prevention are community based and do not have a direct link to research that would examine the efficacy of their activities.

In summary, the research on prevention and intervention is only at an early beginning stage. Most of the information found in this report refers to ongoing programs who are just starting to evaluate the quality of different interventions. The need for prevention has been thoroughly identified, while the scope and focus on actual prevention programs remains narrow. Within the scope of this search the great majority of activities are focused on prevention, while information on the actual interventions at different ages and stages is extremely limited. This suggests that a focus in future research should be directed towards implementation and evaluation of intervention programs.
State of the Evidence: Fetal Alcohol Spectrum Disorder (FASD) Prevention

Executive Summary
November 30, 2004

Principal Investigator: Dean Lynn Basford

Co-Principal Investigators: Dr. Karran Thorpe and Dr. Robert William

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ACKNOWLEDGMENTS
We would like to acknowledge Ms Alyssa Reid who served as research associate in the initial stages of this project.
Executive Summary

Purpose
The demands of practice on health care professionals and policy makers to critically review and utilize new knowledge in view of their time constraints and relative lack of expertise in synthesizing a great deal of information are becoming much more difficult. The purpose of this study was to partially address this difficulty in one topic area by reviewing and evaluating the state of the evidence regarding Fetal Alcohol Spectrum Disorder (FASD) prevention. The result will be an easily assimilated synthesis of what is known about FASD and will include recommendations to inform policy, direct ‘best practice’ and give guidance for future research.

The overall aims of this study were to produce a current understanding of the global incidence and prevalence of FASD; synthesize the scientific knowledge within the frameworks of biological, psychological and social domains; identify markers of people at risk as determined in the literature including any biological markers as well as genetic or cultural susceptibilities; identify the effectiveness of preventative models; examine the preparation of health professionals who work in this field; identify policy directives that include alcohol and legislative restrictions and examine their effectiveness; and, examine and report on ethical dilemmas.

Method
A multidisciplinary team carried out this review using a Cochrane-style systematic review methodology. A key component of the review was the double-blind readings of all documents identified in a large scope literature search by two independent reviewers.

Data Sources
Comprehensive searches were carried out in over 25 bibliographic and full-text databases, six library catalogues, and over 50 World Wide Web sites to identify both qualitative and quantitative studies as well as relevant monographic and “grey” literature. Further, reference lists of all studies were checked for additional significant references and key journals were hand searched. This data collection process continued within the given time constraints until the databases were exhausted.

Study Selection
Studies were selected if they were judged to be relevant to FASD prevention and of highest quality. Document quality was ranked according to a three-point categorical scale: 1 (poorly done), 2 (average), and 3 (exceptional, that is, ground breaking or seminal research, rigorous methods applied). Studies were selected if they had been categorized as a “3” quality level by both independent reviewers. Selected studies, coded “2” quality, were also included, mainly for illustrative purposes. All studies coded “1” were excluded. A total of 1345 documents were identified of which 937 were selected and reviewed. Of the 937 documents reviewed, approximately 370 met the standards of quality and relevance, and were included in the systematic review process.
**Data Extraction and Synthesis**
As noted previously, each study was reviewed independently by two reviewers. Using an electronic data extraction form designed especially for this project, each reviewer recorded quantitative and qualitative data describing the study’s objectives, methodology, findings, conclusions, and significance. Following the independent reviews, team members met as a group to compare and discuss their findings and to resolve any differences of opinion as to the quality and inclusion of particular studies. Data from the extraction forms were recorded in a database, which was made available to all team members following the blind-review phase of the project.

**Findings**
The literature regarding prevention of FASD highlights the lack of consensus surrounding almost every aspect of the effects of alcohol consumption during pregnancy on the fetus right from incidence and prevalence through risk and protective factors to prevention programs and strategies. The state of the evidence is such that there are a number of very well done experiments and reviews but there are also a number of papers that were not as rigorously designed.

Historically, reports of a relationship between parental alcohol consumption and negative consequences for offspring indicate that this topic is not new even if there is some dissention about the degree or import of said knowledge. Some writers suggest such references are a clear indication of early awareness of the potential consequences of alcohol consumption during pregnancy (e.g., Armstrong, 2003; Danis, 1981) while others assert these same references have been taken out of context and have entirely different meanings (e.g., Abel, 1984).

**Definitions**
This disorder has been known since the early 1970’s as fetal alcohol syndrome (FAS). Many definitions of Fetal Alcohol Syndrome (FAS) have been put forward in the literature but most facets of these definitions have been captured in the definition of FAS offered by Abel and Hannigan (1995). Accordingly, we have adopted this definition as the standard for this review. Currently, however a new term – fetal alcohol spectrum disorder (FASD) has been in use to encompass a range of related disorders. During our reading of the literature, it became obvious that an encompassing definition of FASD needs to include a summary of the differences among the various aspects of the disorder (i.e., FAS, Fetal Alcohol Effects [FAE], Alcohol Related Neuro-Development [ARND], Alcohol Related Birth Defects [ARBD]). Thus, we expanded the definition to explain and define these related disorders. In addition, we compiled a succinct synthesis of the most common symptoms of each facet discussed in the literature reviewed here that is current compared with those offered by Stratton et al. (1996) and Abel (1998).

**Theory**
This review is “evidence based.” However, as theory helps inform and explain what we learn, we identified that a significant gap in the literature is in the area of theory driven explorations of FASD. While many studies could easily be placed in certain theoretical contexts, few studies explicitly explore the theoretical frameworks in which knowledge grows and is disseminated. For example, many gender-based theories could easily apply to the sociological understanding of the growing awareness of FASD in North American society. Similarly, stages of grief could apply to coping with FASD.
children, and certain social marketing theories could be applied to better design broadbased primary prevention strategies.

Our group felt it necessary to expand upon or, on occasion, add theoretical components to accompany the analysis of the literature in each member’s respective disciplines to help practitioners and policy makers gain a clearer understanding of the concepts before applying them in the practice arena.

**Epidemiology and Demographics**

Difficulties in diagnosing and underreporting FASD arising from practical and methodological discrepancies also contribute to the difficulty of identifying the rate of FASD, who has FASD, and who is most likely to be at risk for producing an FASD child. Rates of FASD reported in the literature range widely from a low of 0.1 per 1000 live births (CDC, 1997; Egeland et al., 1998; Miller et al., 2002) to a high of 14.8 / 1000 (Williams et al., 1999) and, one study from South Africa even reported numbers as high as 46.4 per 1000 live births (Parry, 2000). A great deal of these differences are due to who comprises the study population (i.e., target a high-risk population = high rate), missed diagnoses (= low rate), and difficulties with assessment tools. Moreover, the political climate also has a bearing on the reported rates of FASD. For example, North American rates of FASD have been higher than those of France, Italy, the UK or Russia. However, this finding may be due, as one study from Australia asserts, to the lag these countries have experienced in FASD research in comparison to the US and Canada – you can’t find what you don’t look for. Rates can only be reported if health professionals are prepared to make an accurate diagnosis. To do so, they need appropriate tools. This review enumerated a number of assessment tools identified in the literature for measuring alcohol consumption. Certain tools such as TWEAK and T-ACE are identified as yielding consistent and accurate results (Russell et al., 1994, 1996). Similarly, rates of FASD are dependent on diagnosis, which is confounded by the vast numbers of potential symptoms and indicators. Thus, assessment of FASD is further dependent on the tools utilized to assess the presentation of symptoms in the infant and our review uncovered a number of successful tools (4 digit diagnostic code, Astley and Clarren, 2000; Photographic analysis software, Astley and Clarren, 1996) and some less successful tools (e.g., FASSCREEN, Burd et al., 2000).

**Risk Factors**

Risk factors have been shown to be a two-pronged issue – risk factors that may contribute to women consuming alcohol during pregnancy (e.g., culture, SES) and risk factors that may result in FASD (e.g., environment, age, previous births). These factors are generally addressed separately even though the first contributes directly to the second. There is disagreement in the literature on the risk factors for FASD beyond alcohol consumption during pregnancy (i.e., high blood alcohol content and binge drinking pattern). We endeavoured to clarify this issue by compiling a summary of all risk factors known to date (e.g., environmental, genetics, culture, SES). Some studies identify cultural risk factors while others find that low socio-economic status is more likely to predict FASD than is culture. White, older middle-class women with a higher educational status are at risk for drinking during pregnancy but risks for drinking during pregnancy do not necessarily equate to risks of having an FASD child. High blood alcohol levels associated with binge drinking appear to be more likely the cause of fetal effects and these drinking patterns are found in different populations. Risk factors do not appear to differ significantly on any cultural basis although Native or other minority culture women are often ‘screened’ for substance abuse more than Caucasian women.
Co-morbidity
Part of the difficulty in identifying risk factors is the complexity of the disorder and the relative lack of knowledge regarding the biological mechanisms that culminate in FASD (i.e., threshold for consumption, timing of drinking during pregnancy, paternal impact). Potential co-morbid factors have been identified, such as smoking and other substance abuse, all of which have deleterious effects on the fetus and are often consumed concurrently with alcohol. However, due to inaccurate self-reporting and other methodological difficulties, few researchers have been successful in isolating how substances, or combinations of substances, impact fetal health and this conundrum makes mapping relationships among key factors difficult. Poor nutritional status has also been identified as contributing to FASD.

Protective Factors
The identification of protective factors is confounded by many of the same difficulties with which other aspects of FASD research are beset. Lack of knowledge and understanding of the exact mechanisms of the effects of alcohol on the fetus also make identifying protective factors difficult. From the literature it is possible to identify some measures that can be taken to minimize the effects of alcohol consumption during pregnancy including, but not limited to, improved nutrition, enriched environment, and taking folic acid during pregnancy. More information on potential protective factors is coming out of animal studies.

Animal Studies
Much of that which is new in FASD research-based literature has come from animal studies. For example, neuroscience-based research programs are having success in finding definitive answers regarding the mechanisms of FASD. Peak blood alcohol level has been identified as an important determinant of whether FASD occurs than amount of alcohol consumed or even drinking pattern, although binge drinking is more dangerous than drinking one or two drinks every day for a period of time. These studies are also confirming and expanding what is known about the effects of alcohol on the fetus. For example, although the effects of alcohol on the fetus are dependent on when in the pregnancy the consumption occurs, researchers are now aware that the brain is affected in all three trimesters but different parts of the brain are affected on different days. Rat studies are also indicating there is some genetic component to FASD because they have identified some rat strains with resistance to the effects alcohol despite being unable to breed for this effect. Animal studies have also shown evidence regarding a variety of protective factors and note that the sperm of the father is also adversely affected by alcohol consumption. The main problem with animal studies, however, is the difficulty in applying results to human populations.

Policy
The best policy for dealing with FASD is clearly prevention. Governments and health care agencies in North America show a degree of consistency in the literature with virtually all policies advocating total abstention from alcohol consumption during pregnancy. Historically, however, this position was not always the case. Even today, worldwide, there is some dissention toward the policy of total abstention. Canada and the US prescribe zero consumption whereas the UK policy suggests one or two drinks per day are safe. Some writers suggest that with no clear evidence those minimal amounts of alcohol consumption cause FASD that advocating total abstinence is akin to “crying wolf” and that it may cause unnecessary worry and stress on a pregnant woman who has consumed small amounts of alcohol.
The other side of this argument, however, states that with no known threshold amount of consumption beyond which fetal damage is done, it is better to be safe rather than sorry.

Subsumed in the overall suggestions to avoid any alcohol consumption during pregnancy are policies to realize this positive behavior. Among various initiatives is the US Government beverage labeling policy that requires warning labels on alcohol containers even though evidence for the efficacy of this policy is lacking. Another troublesome policy being followed by some states is to support the punitive approach, which advocates criminal sanctions against women who drink during pregnancy. This policy is often carried out through modifications to existing child abuse laws and has only been “successful” in prosecuting one case (Deville et al., 1998). The literature indicates that this practice is a dangerous route ethically and practically with the very real possibility that women who drink will not seek health care during pregnancy out of fear of prosecution or, perhaps, they will seek an abortion rather than risk criminal sanctions.

Prevention Strategies
Prevention strategies encompass three categories: primary strategies, which are broad based and aimed at educating the population generally; secondary strategies, which are more selective and target those at risk; and tertiary strategies, which are strategies designed to prevent further difficulties for those already affected by FASD. Consensus for these categories exits in the literature even if some studies use slightly different terminology.

Primary Preventive Strategies
Social marketing is generally a primary prevention tool. A prime example is the policy calling for warning labels placed on alcoholic beverages in the United States. Such programs can be both educative and legal, but follow-up studies suggest these strategies are only of limited efficacy. In spite of this relative lack of success, social marketing theory espouses that this approach is worthwhile and well designed primary prevention programs can impact in a positive manner.

About 40% of women continue to drink during pregnancy even when they know about the risks. Eighty percent of women decrease their consumption upon learning of a pregnancy, but only 60% quit drinking alcoholic beverages completely. Those women who continue to drink do so because they see no other socialization alternatives available and have less motivation to quit drinking. Social marketing or social change strategies have been employed to promote abstinence among pregnant women. Three broad-based approaches have been utilized: education only (media campaigns), legal approach (warning labels in US), and community based programs. Media campaigns and warning labels have had some success in effecting behavior change through awareness; however, community-based programs have only been effective with addicts.

Educational programs have had some success in preventing FASD. Targeted education to assess current knowledge awareness of fallacies and increasing awareness of alcohol effects has increased women’s knowledge of the timing and nature of possible effects of alcohol consumption. In follow-up studies, both female and male students were able to identify the links between alcohol and FASD. Information provided to junior-high and high-school populations regarding alcohol consumption and the direct links to FASD has increased knowledge of alcohol effects in general. Again, follow-ups with female students
indicate that they will not consume alcohol during pregnancy. These results indicate that curriculum inclusion of education on the effects of alcohol consumption from elementary to post-secondary settings to educate females prior to, and during, childbirth years is effective in reducing FASD. Further, educating women on the risks of drinking through counselling and providing guidance to improve nutrition and reduce environmental risk factors have had some success. Therefore, it is recommended, in addition to the education of health care professionals to better assess alcohol consumption and diagnose FASD as a primary prevention tool, that those working in educational settings (e.g., counsellors, health teachers) must become more knowledgeable in order to disseminate alcohol and FASD information through adolescence.

Culturally, primary prevention has followed the practice of exploring the kinds of information possessed by Native Indian women as well as their drinking practices when they learn about their pregnancy. It is recognized that prevention programs can be effective in increasing knowledge among Native women. In one study, O'Connor and Whaley (2003) noted that the best predictor of post-conception alcohol consumption was the woman's high-risk drinking score as measured by the TWEAK. It is also acknowledged that more FASD programs are available in rural areas and on reservations than in urban areas for Native people. This finding causes concern for the large proportion of women in urban settings who do not have access to culturally specific prevention programs. Unfortunately, researchers, who pursue culturally diverse populations, also inform us that Native Indian women are often predisposed to drinking behaviour because of their upbringing within familial tendencies to excessive drinking by their parents and spouses or partners. Further, they tend to use alcohol as a means of escaping abuse. Within such environments, when educational opportunities are limited, researchers in the southeast US observe that young women of African-American, Hispanic, and White descent, are likely to follow this behaviour, too. Researchers in Southern California note that Native Indian women often lose their children as a direct result of their addiction to alcohol. In their work with Northern Plain Indians, Kvigne and colleagues (2003) conclude that intervention is critical for women who have an FASD child, because successive children with FASD demonstrate even more dramatic effects. Again, the need to prevent this tragedy is paramount.

Secondary Preventive Strategies
It has been shown that just learning of a pregnancy has been stimulus enough for women to decrease their drinking, suggesting there is an optimum time window to reach women at risk. Nevertheless, to effect long-term change, follow-up programs will be necessary. Targeted information regarding alcohol consumption and FASD within prenatal clinics has shown some positive changes in the behavior of pregnant women both during and post pregnancy. This change includes abstention and decreased alcohol use. Counselling sessions coupled with information to reinforce educational efforts has proven to be the most effective strategy. Success in programs from Washington State and Toronto, Canada indicates education of women at risk in the areas of the risks of alcohol consumption and the value of improved nutrition and other protective factors can improve birth outcomes.

Tertiary Preventive Strategies
Tertiary prevention is designed to ameliorate the symptoms and problems of those already affected by FASD. These programs include treatment for substance abuse, training to provide enriched environments that may improve the life quality expectancies of those impacted. Coping with FASD
(discussed later) is primarily a tertiary preventive strategy. The key to tertiary prevention policy is leadership provided through meaningful policy emanating from government departments, (e.g. vehicle, social and health departments).

**Best Practice**

It is clear from the literature that prevention is the best solution to the problem of FASD. What is less clear is what “best practice” is in terms of prevention programs. Early identification through tested screening tools, such as those discussed earlier, of those women at risk for alcohol consumption during pregnancy is the first step. But, the picture becomes less clear regarding how to identify these women. Again, epidemiological issues regarding those women who drink during pregnancy make identification of a high-risk group problematic. It is apparent that better practice is to identify women at risk through psychological or caring, rather than punitive, approaches. A variety of programming models have been utilized to address FASD: addictions, FASD prevention models, child abuse prevention, mental health/addictions, teen parent, culturally based, judicially based and educationally based. The Seattle model is the most often cited for purposes of prevention. Several other apparently successful models have been developed from this Seattle model. Characteristics of a successful home visitation program as identified in the literature contain common elements: an intensive level of service that is responsive to client growth; they are relationship based; trust must be gained and perseverance practiced; role models; strength based; non-judgmental; client/family centered; and helping clients to obtain appropriate services such as food, shelter, safety, diagnosis, addictions treatment, social services, legal support, domestic violence support, counselling and keeping the client connected with any children in care. Successful models need to be developed specifically for women, that is, alcohol treatment has not been overly successful for men and these programs are even less useful for women. The Karolinska Project for early treatment of women with early alcohol problems (Dahlgren & Willander, 1989) has illustrated the importance of ‘woman-based’ treatment with long-term follow up for success in helping women at risk avoid alcohol and, therefore, not risking an FASD child. Ultimately, it does not matter to what group a woman belongs, culturally or economically, outreach programs and education are the keys to reducing FASD.

**Coping with FASD**

There is a dearth of literature that addresses the concept of coping with FASD. Beyond some tertiary prevention programs designed to ameliorate further effects of FASD there is little mention of programs to assist family members, or even health care professionals, in coping with the impact of a diagnosis of FASD. We examined the various individual characteristics identified as risk factors for producing a child with FASD and considered how these factors (e.g., gender, educational level, cultural differences, SES, social support such as family members also not drinking) affect the coping abilities of the family members involved. However, it is important to note that a search of the literature formulated towards intervention in a broader sense may well be more successful in addressing this issue than the search we conducted, which was directed towards prevention programs and did not access much of the literature aimed at teachers, parents, and health providers on assisting FASD children with maximizing their potential.
Relevance to Health Services and Policy Makers
Health care professionals and policy makers need to be competent to practice. Their knowledge and skill must reflect the most up-to-date knowledge possible. Unfortunately, the state of knowledge regarding FASD is a moving target, continually growing and changing through active research programs. The sheer volume of knowledge makes it exceedingly difficult for health care professionals or policy makers to remain current and to sift through what is relevant, what results might be spurious, and what is new to the field. The value of a study such as this systematic literature review is to examine the state of the evidence, weed out what is not relevant or has been replaced by newer understandings, and present what remains in a clear, concise, and usable format so health care professionals can easily assimilate the knowledge and apply that knowledge to their practice in the most efficient, effective, and economic manner possible.

This review identified that animal studies show that alcohol consumption at any level does cellular damage and this information supports the policy of recommending total abstinence. Further, the lack of a standard approach to diagnosis and measurement of both alcohol consumption and FASD impacts measuring prevalence of FASD, which, in turn, impacts policy. We recommend compulsory reporting of FASD cases to a centralized database to allow for full knowledge of prevalence to better enable planning, implementing research programs, and developing sound policy. Advocating abstinence is appropriate but the literature clearly illustrates that policy promoting the punitive approach is neither ethical nor effective. It is clear that resources need to be invested in programs to eliminate the occurrence of FASD, that is, woman-specific education programs that are culturally sensitive.

What is Missing
Some of the areas that are lacking in the FASD literature reviewed here have been discussed previously in this summary. However; several key areas need to be addressed to deal effectively with FASD. The need for consistent education of health care professionals in assessing alcohol consumption as well as assessment and diagnosis of FASD is evident. There also appears to be a gap in the knowledge of the effectiveness, efficiency, and economy of programs in practice. There appears to be a lack of knowledge and understanding of the mediating effects of various micro-nutrients (protective factors) in the human form and a concurrent lack of understanding of how genetic implications from animal studies may apply to human subjects.

Conclusion
The state of the evidence regarding the prevention of FASD is not as advanced nor as clear as one might expect given the length of time the various incarnations of FASD have been known and explored. Through a comprehensive, systematic review such as this one, following rigorous methodological guidelines, deficient research areas can be identified. It is only after problem areas are identified that they can be addressed.

This project accomplished the following goals:
- We extensively surveyed the existing literature and found there was little consensus on several key areas of FASD knowledge.
- We also found a state of confusion in the presentation of what knowledge is available.
- We took what is known and reformulated it into a concise, understandable and usable format.
• We suggested what assessment tools and programs are the best tested and efficacious.
• We identified areas where knowledge is lacking and these areas may well provide the outline for future research programs.
• We also offered our own model for best practice for FASD prevention.

Implications for Future Research
The gaps in knowledge also offer the next best research opportunities. We need to evaluate ways to best educate and train health care professionals to screen for alcohol use and to diagnose FASD. Formal evaluation of promising prevention programs is required. Research measuring the success of culturally sensitive best practice models is also needed. Animal studies are providing very promising results for identifying specific mechanisms and timing of FASD and further research in this area can only be helpful. The better we are able to identify and understand the way alcohol affects the fetus the better we will be able to design prevention programs. We need to evaluate ways to administer and measure application of animal research that indicates certain agents (e.g., antioxidants) provide protective effects to a human model. The lack of theory-based research suggests another area of future research that will help to expand understanding of FASD and the impacts it has on the lives of all who come into contact with children affected by it. Even basic epidemiological studies utilizing definitions and measures of alcohol consumption that are accepted worldwide as standards are needed to fully understand how much FASD is out there and who it most affects. This review has highlighted a number of areas where further research could and should be carried out. Instead of re-visiting old ground, new research must utilize standardized definitions, screening tools that have been proven to be effective, use truly representative samples, and be directed at the areas that have been identified here as lacking.

Recommendations for Education
• Education is required to inform health professionals on the positive and negative health coping strategies that can serve to prevent the necessity for secondary and tertiary interventions.
• Health professionals require a comprehensive understanding of, and the necessary skill to undertake assessment and diagnosis of FASD/FAE.
• Health professionals need to understand theoretical frameworks that underpin best practice and prevention intervention strategies.
• Health Professionals need to be able to work Inter-professionally, and within inter-agency frameworks so as to provide the best possible health outcomes for their clients and their families.
• Health professionals need to explore the health beliefs of clients and their families to improve health outcomes through compliance with the necessary behavioural changes.
• Health professionals need to have knowledge of prevalence and incidence gathering modalities so that they can contribute to the data gathering of incidence and prevalence of FASD/FAE.
• Health Professionals require knowledge of protective factors such as antioxidants and the role in which they play in the prevention of FASD/FAE.
• Health professionals require a sound grasp of social marketing theories, their effectiveness and efficiency in preventing FASD/FAE.
• Health Promotion and Health education should be the central focus of health professional’s work. In essence, health prevention is everyone’s business.
• Education relating to the effects alcohol consumption has on the fetus should be undertaken in all schools, with adolescent women and men, communities and
wider population groups, using a multi-media approach that is culturally sensitive.

- Cultural diversity issues must be understood and applied in clinical practice.
- Education within the clinical setting can be most effective therefore, health professionals must seize every opportunity to inform the public and target meaningful education to women at risk.
- Revise basic health curricula to include knowledge, skill, understanding and experience of FASD/FAE.
- Provide training and knowledge for all health care professionals about related support and resources available to them in treating FASD. This should include support and resources geared to diagnosis, intervention and prevention of FASD.

**Recommendations for Practice**

- Practice models/instruments should incorporate coping assessment as part of their screening approach.
- Use a multi-service surveillance system to develop and offer appropriate services to children and their families including prevention strategies for women in child bearing years.
- National pooling of FASD research findings and best practices for dissemination should be applied in the practice setting as part of evidence based strategy.
- Health educators in a variety of clinical settings should unite to come in contact with women of childbearing age in order to disseminate information related to alcohol consumption during pregnancy.
- Highlight the need for early diagnosis of FASD/FAE so that appropriate interventions can be established over the life of the child.
- Prevention programs for women should provide a range of services such as brief interventions, counseling, social support, prenatal classes, parenting classes and mental health services.
- Incorporate evidence from scientific enquires to provide a framework for evidence based practice.
- Develop good inter-agency and multi-professional working relationships and communication systems using a client centred electronic record system.
- Include male partner in programming.
- Empower communities to assist in prevention programs.

**Recommendations for Research**

- Evaluation of promising prevention programs
- Studies utilizing large, representative native populations to measure factors that put women at risk such as: socio-economic factors, environment, cultural norms, health beliefs, nutritional state; and social support systems.
- Investigations into the ways in which women and families cope with FASD/FAE, measuring those that have a positive health outcome and those that produce negative outcomes.
- Development or adaptation of health coping assessment tools used with FASD.
- Multigenerational research to determine the influence of family circumstances and habitus.
- Assess the reasons why women do not engage in treatment programs.
- Evaluate the effectiveness of antioxidants as a protective substance to alcohol abusing pregnant women. (there have been no human trials to date).
- Undertake research to establish the true nature of mediating factors such as genetic make-up, nutritional state of the women, and their physical, psychological, social, and spiritual wellness.
- Undertake research to evaluate the effectiveness, efficiency and economy of programs in practice.
• Explore the effects of various environmental factors.
• Further examine the threshold limit of alcohol consumption pre-conceptual, during pregnancy and through the period of lactation.
• Explore the relationship of FASD and Binge drinking through longitudinal and cross population studies.
• Explore factors that could put Canadian Native women at risk for producing children with FAS. Bray and Anderson (1989, p. 44) recommend that research be conducted to assess the consumption of alcohol among Canadian Native women in specific communities.
• Use larger samples and cross-sections of Native populations to enhance generalizability. Shostak and Brown (1995) also note the need to include Indians who reside on reservations and those who live in rural areas.
• The psychometrics of instruments need to be assessed. This information supports the identification of appropriate tools to be used and gives credibility to the findings (Shostak & Brown, 1995).
• What are the effects of early diagnosis and intervention, loving and knowledgeable family, and educational opportunities on children? The effects of these situations remain unexplored (Shostak & Brown, 1995, p. 43).
• Increase accessibility to all forms of family planning. Kvigne et al. (2003) note that Northern Plains Indian women tend to choose sterilization as a means of birth control, in large measure, due to a lack of accessibility to other forms of family planning.
• Ensure educational materials are written at an appropriate reading level. Given the educational level of many Native women is lower than Non-Native women, educational materials need to be appropriate or many women will not have access to basic information (Kvigne et al., 2003).
• Larger samples and comprehensive assessments are needed to determine the variables that may predispose women to continue drinking once pregnancy is known. O’Connor and Whaley (2003) suggest that variables might include: education about risks of drinking during pregnancy, role of drinking behaviour of significant others, personal characteristics of those women who continue to drink (e.g., depression), and the use of other teratogens such as nicotine.
• Develop campaigns and interventions to provide factual information to help at-risk women reduce their drinking during pregnancy. Kaskutas (2000) states women’s responses to health-warning messages is less than anticipated. In fact, many women said the warnings made them feel negative about themselves, rather than conveying an important message about drinking behaviours.
• Treatment outcomes are needed. Streissguth (1994) indicates that the effectiveness of play therapy, insight-oriented therapy, or group therapy have not been identified through research. Nor is there any research on the efficacy of medications for treating persons with FAS/FAE.
• Further examination to establish biochemical markers.
• Examination of co-morbid substance use effects in relationship to the development of FASD/FAE.
• Evaluation of the effectiveness of various screening tools through which a universal approach can be had.
• Evaluation of home visitation models over a longitudinal period.
• Scientific collection of data needs to be the basis of evaluation rather than the use of client self report.
• Dissemination of scientific evidence should reach practitioners working in the field so that they can critique its usefulness, and if appropriate apply in the practice setting.
• Examine the relationship between the advantages and disadvantages of using professional advocates versus para-professional advocate.
**Recommendations for Policy**

- Policy should encourage and support informal and formal positive social support.
- Establish a universal policy directive that supports zero alcohol tolerance during pregnancy and throughout the period of lactation, if supported by sound evidence.
- Invest resources in programs to eliminate the occurrence of FASD. Shostak and Brown (1995) suggest that professionals unite in supporting one another in the prevention of FAS. This recommendation is also supported by Kvigne et al., 1998).
- Include all community stakeholders when developing health promotion programs for American Indians or other cultural groups. (May & Moran, 1995). This recommendation is important given the desire of most, if not all, Aboriginal peoples to be self-governing. Although sharing information from successful programs is appropriate, it is recognized that programs need to be adapted for use in any community.
- Use existing policies that have been shown to be effective for purposes of developing policies for American Indians (May & Moran, 1995). This notion is supported by most researchers who readily acknowledge that success of policy and laws regarding use of alcohol in any community are dependent upon direct and committed community involvement.
- Establish a standard approach to diagnose and measure prevalence that impacts policy, for example compulsory reporting of FASD cases to inform a centralized data base system.
- Invest resources in programs to eliminate the occurrence of FASD/FAE such as women-specific alcohol programs, culturally sensitive programs, and education.
- Reconsider punitive approaches that are neither ethical or effective.
- Focus on the fact that FASD is not a women’s issue it is one in which society at large must take active responsibility.
- Policy and resource allocation for developing competence in FASD for healthcare workers.
- Direct curricula in schools, health curricula to address FASD/FAE in a comprehensive manner commensurate with levels of understanding.
State of the Evidence: Interventions for Children and Youth with a Fetal Alcohol Spectrum Disorder (FASD)

Executive Summary
November, 2004
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EXECUTIVE SUMMARY

PURPOSE AND SCOPE OF THE REVIEW
Alcohol use during pregnancy can have a significant impact with affected individuals experiencing complex patterns of behavioural and cognitive difficulties that influence their functioning throughout the lifespan. In May 2004, the Alberta Centre for Child, Family and Community Research funded this state of the evidence review entitled “Interventions for Children and Youth with Fetal Alcohol Spectrum Disorder (FASD)”. This state of the evidence review provides:
- A synopsis of the existing literature on interventions for children and youth with a FASD;
- A critical appraisal of the current FASD intervention literature to inform policy decisions.

METHODS
Forty peer-reviewed and 23 grey literature databases were searched, including those that covered education, language and linguistics, nursing, medicine, physical education, sociology, social work, interdisciplinary, law, northern studies, Canadian studies, disability and rehabilitation, and women’s studies. In addition, a systematic analysis of Internet sites and review of reports and documents received from key stakeholders was undertaken. All literature used in the review was subjected to rigorous assessment of quality and graded utilizing a five-level grading system. Level I indicated that the information was based on a randomized controlled trial with an adequate sample size to derive meaningful conclusions. Level V indicated that the information was based on the opinions of experts in other fields, or reports of collective wisdom or experience.

KEY FINDINGS
The literature search identified ten studies of which seven studies were included in this state of the evidence review. Interventions in the included studies targeted (a) psychostimulant therapy (methylphenidate, pemoline, and dextroamphetamine), (b) cognitive control therapy or (c) an element of education (e.g. one-to-one tutoring, supplementary reading, or information on neurological deficits) to improve outcomes for children and youth with a FASD. Three studies (two foreign language and one unpublished study) could not be acquired for inclusion in this review. According to the grading scale, most of the identified studies were of poor to fair quality, and hence lacked scientific rigor. Consequently, the analysis of studies provided limited reliable data with which to make recommendations regarding efficacious interventions for children and youth diagnosed with a FASD. The majority of information was gathered from the clinical wisdom of experts, practitioners, and parents. What was evident in this literature was the synergy of information coming from caregivers, professionals from various disciplines, and across diverse settings and geographic areas.

ENEMIES MODEL
A significant contribution of this state of the evidence review was the development of the ENEMIES model, which provides a new and holistic way of understanding the myriad issues associated with FASD. This framework provides a guide for the development of potential interventions for children and youth. The acronym ENEMIES serves to identify important areas for consideration in promoting optimal functioning. ENEMIES refers to Executive Functioning, Neuromotor, Emotional, Medical, Interpersonal, Environment, and Speech/Language.
Executive Functioning
Individuals with a FASD may have problems with any of the following stages of information processing: recording, interpretation, storage, retrieval, and utilization of information. Manifestations: self-regulation and attention difficulties, distractibility, and challenges in organizational and planning skills.
Interventions:
• Cognitive rehabilitation approaches;
• Concrete learning experiences.

Neuromotor
Motor and sensory-motor impairments may interfere with learning and development. Manifestations: feeding difficulties, motor challenges (e.g. muscle tremors), lack of precision or smoothness in walking, hypersensitivity, hyperactivity, and fidgety behaviour.
Interventions:
• Feeding difficulties: cue-based feeding, regular feeding schedule, extending eating periods, appropriate portion sizes, avoiding distractions while feeding, and nutritional support;
• Motor delays: play activities, games, and individualized physical education;
• Sensory-motor impairments: sensory-integration therapy, limiting visual or auditory stimuli, calming environments, fidget toys, and regulation and relaxation strategies.
Advancing the Fetal Alcohol Spectrum Disorder (FASD) Research Agenda

Emotional
Difficulties children have in developing trust and a secure attachment to a primary care giver and social challenges, secondary to the primary disabilities of alcohol exposure, may lead to later disorders in emotional functioning.
Manifestations: attachment difficulties, depression, low self-esteem, and anxiety.
Interventions:
• Supporting parents in interacting with their child in responsive, supportive, and emotionally connective ways;
• Providing emotional support and encouraging autonomy;
• Providing anticipatory guidance for families;
• Openly and truthfully communicating with older children about FASD;
• Frequently recognizing and promoting the child’s strengths may increase his/her self-esteem, positive self-image, and ability to manage life.

Medical
Early diagnosis is critical to early intervention and ensuring that the family and associated professionals develop realistic expectations and understand the challenges associated with a FASD. Early diagnosis is a protective factor as families raising a child formally diagnosed with a FASD experience significantly less distress, conflict, depression, or anger compared to those families raising a child with a suspected, but unconfirmed, diagnosis.
Interventions:
• Access to a diagnosis, preferably an early one, to provide opportunities for the most effective and appropriate supports;
• Using standardized diagnostic criteria;
• Using a holistic multi-disciplinary team approach to understand the unique needs of the individual and required interventions;
• Training for professionals and care providers regarding FASD that includes implications of the disorder across the lifespan;
• Development of screening tools that demonstrate sensitivity and specificity;
• Implementation of a research-based approach to evaluating psychopharmacological treatment.

Interpersonal
Social development in children and youth with a FASD may be compromised and may include difficulties with interpersonal skills and social communication.
Manifestations: weak social skills, and inappropriate behaviours.
Interventions:
• Teaching social concepts in multiple environments to enhance generalizability;
• Implementing social stories to assist with understanding expectations for problematic situations;
• Conducting “Functional Analyses” of inappropriate or challenging behaviours to understand the communicative intent of the behaviour.
Environment
The postnatal environment may mitigate or exacerbate the effects of prenatal exposure. Continuing substance use by the biological mother, domestic instability, and multiple foster placements are environmental factors that may contribute to adverse outcomes. Manifestations: inappropriate behaviour, hyperactivity, depression, and offenses related to criminal or sexual misconduct.
Interventions:
• Positive behaviour support;
• Promoting a supportive parental presence; adapt home and lifestyle to meet the needs of the child;
• Providing a stable, structured, and consistent environment;
• Using visual cues (e.g., picture schedule);
• Teaching functional skills throughout the individual’s lifespan;
• Using “hands-on” learning activities;
• Targeting the “whole brain” by presenting information through multiple modalities;
• Providing respite for families; parent support groups.

Speech/Language
Central nervous system dysfunction observed in children and youth affected with a FASD is observable through speech and/or receptive/expressive language delays or disorders.
Manifestations: superficial conversational fluency, and difficulty processing and responding to incoming information.
Interventions:
• Language stimulation and general language enrichment;
• Targeting speech production skills;
• Reducing competing auditory stimuli;
• Assessing for sensory impairment during early stages of speech and language development.
RECOMMENDATIONS
Given the gaps and limitations of the current FASD intervention literature, the reviewers were unable to formally evaluate the strength of the following recommendations. These recommendations stem from the literature (predominantly levels IV and V), common themes appearing in the reviewed material, and the opinions of the research team. For ease of read, the recommendations have been grouped according to the following categories: individual, family, community, and policy.

INDIVIDUAL
• The clinical wisdom of experts and practitioners in the field has highlighted many apparently effective techniques, which should be used as a basis for beginning to formally evaluate FASD interventions;
• Interventions found useful in other special needs populations (e.g., AD/HD, Autism, Learning Disabilities) may be a useful foundation to generate research on effective interventions for individuals with a FASD;
• Interventions should be child-focused, family-centred, and culturally responsive;
• Interventions should begin early and extend across the lifespan;
• Interventions should be developed based on an accurate assessment of the individual’s capabilities in all facets of his/her life;
• A comprehensive diagnostic evaluation, which identifies areas of strength and need, is critical to develop realistic expectations, secure appropriate supports, and develop effective interventions.

FAMILY
• Future research should aim to identify factors in the mother-infant relationship that may positively impact child outcomes;
• In light of preliminary findings from animal research studies, which indicate that paternal drinking may also play a role in the manifestation of FASD-like difficulties, research examining the impact of paternal drinking on child outcomes needs to be further explored;
• Training and educational opportunities need to be provided to parents, caregivers, and families of affected children. Educational information should provide insight into the nature of the disability, associated challenges, and assist in the development of appropriate expectations;
• Factors which contribute to resiliency in affected children and their families need to be identified.

COMMUNITY
• The effects of alcohol exposure are attenuated or exacerbated by environmental factors. Consequently, individuals working with affected children need to be aware of emerging best practices in order to modify the environment to best support the child’s needs;
• Training and professional development opportunities need to be offered to service providers. Given the evolving state of knowledge in the field of FASD, individuals need to be supported in their ongoing professional growth and development;
• It is recognized that a great deal of work has been undertaken in the area of diagnostic assessment. However, further refinement of quantitative and objective ways of diagnosing a FASD (i.e., the development of a “gold standard”) need to be developed for use across Canada.
POLICY

- The Canadian Paediatric Society has recommended that diagnostic and treatment services should be publicly funded and available to all Canadians regardless of ethnicity, status, place of residence, or income;
- Time and resources need to be allocated to design a Canada-wide surveillance system to monitor the occurrence of FASD and to determine the scope of the problem. This information will be useful in directing and monitoring the effectiveness of intervention efforts;
- Innovative and cost-effective approaches such as the utilization of advanced practice nurses (e.g., acute and primary care nurse practitioners) in facilitating screening and diagnosis of a FASD should be considered;
- A systematic and comprehensive research agenda needs to be developed with input from the affected child or youth, parents, families, educators, service providers, policy makers, and researchers. Given the multi-faceted nature of the disorder, all levels of government and jurisdictions need to work together;
- When determining the cost-effectiveness of intervention programs, it is important to consider both the quantifiable and non-quantifiable costs of caring for children with a FASD.

These recommendations are not intended to serve as solitary approaches to overcoming the gaps in the scientific literature related to interventions for children and youth with a FASD. Based on this state of the evidence review, a multi-system, multi-level process, with active involvement of the affected individual and his/her family, professionals, and the community is recommended.
Joint Blood Tribe, Lakeland and Lethbridge FASD Project
Final Report submitted to the Alberta Centre for Children, Family, and Community Research

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Key features of the Joint Blood Tribe, Lakeland, and Lethbridge Project on Effective FASD Prevention.

The Canadian Centre of Behavioural Neuroscience of the University of Lethbridge in partnership with the Blood Tribe Department Health Inc., the First Steps for Healthy Babies Program, Chinook Health Region First Steps and Lakeland Centre for FASD agreed to work together in an interdisciplinary research project on Fetal Alcohol Spectrum Disorder.

1. OBJECTIVES
   The research project had two primary objectives and various secondary objectives. The primary objectives were:
   1. To establish the level of effectiveness over a one-year interval of an interventionist prevention model for Fetal Alcohol Spectrum Disorders (FASD), involving high-risk women recently implemented in two communities, the Blood Reserve and the City of Lethbridge, interacting with the two First Steps for Healthy Babies programmes in those communities.
   2. To establish the level of functional deficits in the areas of psychological and neuropsychological functioning in high-risk women that may be a consequence of FASD and contribute to lack of effectiveness of traditional education and service interventions.

ADDITIONAL BENEFITS
   In addition to the primary research outcomes, the program should provide five benefits:
   1. Both projects would entail further developing relationships and partnerships among colleagues of the Blood Tribe, in Lethbridge service agencies, Lakeland Centre for FASD, and the social science and health science researchers at the University.
   2. A legacy effect—the research would lay the foundation for more complete longitudinal studies of benefits of prevention programmes, exposing service providers to research activities and practices and exposing several more basic researchers to the practicalities and circumstances of research in this kind of service context.
   3. We will provide training to First Nations research assistants enabling development of research competence to implement their own research projects.
   4. If we find clear evidence that the programmes are effective primary prevention of FASD, that is if we can demonstrate a decrease in number or probability of FASD births caused by participation in the programmes then there are strong implications for policy decisions. For example, it will be possible to calculate an approximate cost–benefit analysis, factoring in the anticipated number of FASD births prevented, the life-time extra costs of providing services to an FASD individual, and the costs of the prevention programmes per prevented FASD birth. A demonstration of effectiveness in reducing FASD incidence should positively influence policy decisions across Alberta and, more generally, Canada.
   5. There is a significant service component to this project. Three advocates/mentors will be added, with additional training opportunities: one to each of the primary prevention programmes in Standoff, Lethbridge, and Lakeland.
Prenatal Alcohol Exposure and Child Development at 2 Years of Age

Final Report submitted to the Alberta Centre for Children, Family, and Community Research

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Summary

The Meconium Alcohol Screening (MEC) Study was initiated based on increasing regional and national interest in exploring methods for early identification of children at risk for developmental delay as a consequence of prenatal alcohol exposure. There is a tremendous cost to society and families associated with caring for individuals with a Fetal Alcohol Spectrum Disorder (FASD). Currently, children are often not diagnosed until late childhood and there are missed opportunities for early interventions. Early identification holds promise for earlier intervention, improved outcomes and decreased family and societal costs. Screening of meconium for fatty acid ethyl esters (FAEEs), ethanol metabolites produced by the fetus, has been proposed to identify infants at risk of deficits associated with prenatal alcohol exposure. The T-ACE, a standardized alcohol risk questionnaire, is currently used in Alberta to identify at-risk pregnancies. In this prospective population-based cohort study of women attending Calgary maternity clinics (2002-2005) the association between two screening modalities, T-Ace and meconium FAEEs, and child development at 2-years of age was examined. Participants completed perinatal questionnaires including questions about lifestyle, psychosocial factors and the T-ACE. Meconium was collected and analyzed for FAEEs. At 2-years of age child development was assessed by standardized psychometric assessment (Bayley Scales of Infant Development) and standardized questionnaires.

There was no association between maternal report of alcohol use and FAEE concentration. At 2 years of age, elevated FAEE, weekly maternal prenatal alcohol use, male sex and maternal age greater than 35 were associated with an increased risk of motor delay in children. There was no association between T-ACE and child development measures. However, T-ACE was associated with several prenatal alcohol risk behaviours. Further research is required to understand the factors that modify FAEE production, whether motor delays persist as these children age, and whether interventions for children identified at birth with high meconium FAEE concentrations are effective.

Executive Summary

Screening of meconium for fatty acid ethyl esters (FAEEs), ethanol metabolites produced by the fetus, has been proposed to identify infants at risk of deficits associated with prenatal alcohol exposure. The T-ACE, a standardized alcohol risk questionnaire, is currently used in Alberta to identify at-risk pregnancies. In this prospective population-based cohort study of women attending Calgary low-risk maternity clinics (2002-2005) the association between two screening modalities, T-Ace and meconium FAEEs, and child development at 2-years of age was examined. Participants completed perinatal questionnaires including questions about lifestyle, psychosocial factors and the T-ACE. Meconium was collected and analyzed for FAEEs. At 2-years of age child development was assessed by standardized assessment (Bayley Scales of Infant Development, BSID-II) and standardized questionnaires.

There was evidence of an association between motor delay as assessed by the BSID-II Psychomotor Development Index (PDI) at 2 years of age and concentration of FAEEs. Approximately 50% of the children who had a concentration of FAEE ≥ 500 ng/g in their meconium were found to have delayed motor development. On linear regression FAEE ≥ 500 ng/g in meconium was associated with a decrease on the PDI of 8 points. In logistic regression analysis an AOR of 9.0 was found for FAEE ≥ 500 ng/g after adjustment for infant sex, report of daily alcohol use prior to pregnancy recognition and maternal age greater than 35 years at delivery, indicating that the odds of having motor delay for children with a FAEE concentration above this level was approximately 9 times that of
children with lower levels of FAEE. Children with elevated FAEE tended to be slower in reaching their gross motor milestones. Daily alcohol use prior to pregnancy recognition, male sex and maternal age greater than 35 years at delivery were also associated with motor delay at 2 years of age. There was no evidence of association between FAEE concentration and other child mental development and behavioural outcomes examined. Women with a positive T-ACE were more likely to report alcohol use at all points during pregnancy including binge drinking and regular alcohol use. The women identified by the T-ACE also reported a history of binge drinking, alcohol problems, current alcohol use and alcohol use in previous pregnancies. There was also no evidence of association between T-ACE score and motor and mental development.

This study demonstrated that FAEE concentration in meconium is associated with motor delay in children at 2 years of age. In addition, the delay seen in motor development is consistent with that described previously in the literature for prenatal alcohol exposure. Psychomotor delay may be the most easily identified sign of developmental delay associated with prenatal alcohol exposure in children in this age range. However, any relationship between FAEE concentration in meconium and child development is likely complex. Approximately half of the subjects with elevated FAEE were not delayed. In addition, it is unclear whether FAEE in meconium is a biomarker for alcohol ingestion alone or if other factors may also lead to an elevated concentration of FAEE in meconium.

**Recommendations**

The following recommendations are made based on the study results.

- There was evidence of an association between FAEE concentration in meconium and child motor development. However, there is no evidence at this time that FAEE screening should be used clinically. Without evidence of effective intervention, FAEE screening is not recommended. Drug and alcohol screening should not be stand alone tools used at birth but rather as part of an overall program of integrated mother and child healthcare strategies.

- Physicians should be aware of the prevalence of risk drinking patterns among women who may become pregnant. There was an association between maternal report of alcohol use prior to pregnancy recognition and child motor development at 2 years of age emphasizing the need for physicians to take thorough drug and alcohol use histories from maternity patients and provide assistance or brief intervention as indicated.

- The T-ACE was associated with several risk behaviours related to prenatal alcohol use highlighting the importance of continuing to use this to screen women at risk of pregnancy. The T-ACE has been incorporated into the prenatal record form in several jurisdictions, including the jurisdiction in which this study was conducted, and consequently training efforts should be directed at proper use of this tool for screening and patient care. Women identified by T-ACE or self-report in prenatal or preconceptional visits would benefit from brief interventions and referral for services as warranted as recommended in clinical practice guidelines. Brief interventions prior to and during pregnancy can lead to reduced alcohol intake.

**Further Research**

Further research is required to understand factors that modify the production of FAEE and the utility of FAEE screening:

- Given that an association of clinically significant magnitude is seen it is important to reproduce
these results and build in additional studies to understand the basic biology, clinical utility of FAEE testing, and protective factors for child development for children identified by elevated concentration of FAEE.

- The mothers and the children from this study should be followed up over time. A follow up of the children from the MEC Study is planned for 8 years of age.
- Further research is required to understand the association between maternal genetic, biologic, behavioural and lifestyle factors that may contribute to FAEE production in meconium and how that impacts child development.
- Further research is required to understand the potential effectiveness of a screening program that could involve FAEE screening of meconium and early interventions for mother and child. This information is crucial for the development of an effective screening program.

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Life Skills Training (LST©)
Substance Abuse Prevention
Program for Aboriginal
Children and Youth

Final Report submitted to the Alberta Centre for Children, Family, and Community Research

Principal Investigator: Dr. Lola Baydala

2007
Background
The National Native Alcohol and Drug Abuse Program identified substance abuse as a significant area of concern within Aboriginal communities across Canada.1 Despite these concerns, effective school-based substance abuse prevention programs are not available to the majority of First Nation schools. Prevention programs that are available often fail to capture and integrate the cultural beliefs and values of the community where the program is delivered.2-4 Culturally appropriate drug and alcohol prevention programs are therefore required.

The Alexis Nakota Sioux Nation, located in central Alberta, has a population of 1,566. The community has its own school with an enrollment of 207 students (2007) in Grades K – 12, and an average classroom size of 20 students. During the past eight years, academic faculty at the University of Alberta have worked closely with the Alexis Nakota Sioux Nation providing assessments and recommendations for children with Fetal Alcohol Spectrum Disorder who attend the school. Over time, the need for a school-based drug and alcohol prevention program became evident. This led to further discussions and academic members were subsequently invited by the Alexis Nakota Sioux Nation to participate in a collaborative effort to establish a school-based drug and alcohol prevention program as a part of their regular school curriculum.

A literature review of school-based drug and alcohol prevention programs was completed and the Life Skills Training© (LST) program was chosen based upon numerous randomized controlled trials which have documented it’s effectiveness in the general population.5-8 Although the LST program has been shown to be highly effective in the general population it is a generic program that has never before been implemented with Canadian Aboriginal youth and its effectiveness in this population is not known. Previous research has shown that cultural adaptations to evidence-based prevention programs can significantly improve engagement and acceptability of the program and contribute to growth in community capacity.9- 14 As a first step and in keeping with Aboriginal research guidelines, the Alexis Nakota Sioux Nation extensively reviewed and adapted the LST program to ensure that it incorporated the cultural beliefs, values, language and visual images of their community.

Research Objectives
Our research objectives included the following:
1. review and adapt the three year LST program
2. deliver the first year of the adapted program to grade 3 students at Alexis Nakota Sioux Nation School
3. measure changes in students’ knowledge of the negative effects of drug and alcohol use, attitudes towards drugs and alcohol, and drug and alcohol refusal and life skills
4. document the community’s experiences of and responses to the program adaptations and delivery
5. document longitudinal growth in community capacity

Methods
The Alexis Working Committee was established at the outset of the project and includes members from the Alexis Nakota Sioux Nation, the Women and Children’s Health Community Based Participatory Research (CBPR) Group and the University of Alberta School of Public Health and Faculties of Medicine,
and Extension. The Alexis Working Committee completed terms of reference which served to clarify the roles and responsibilities of each working committee member. The primary role of the Alexis Working Committee has been to oversee general operations of the project including funding, expenditures, timelines, and interpretation and presentation of research results. In addition, an Adaptations Committee was established. The role of this committee was to work specifically on program adaptations. Membership in the Adaptations Committee included community members and school personnel who were also the community representatives of the Alexis Working Committee and included one or more Elders at each meeting. There was also an open invitation for any parent of the school to attend a meeting of the Adaptations Committee at any time.

The Canadian Institute for Health Research, Guidelines for Research Involving Aboriginal People, provided a frame of reference for the work of the Alexis Working Committee and the Adaptations Committee throughout the research process. The proposed work was presented to the Alexis Nakota Sioux Chief and Council and community members, and a Band Council Resolution (A Band Council Resolution is the authority mechanism by which the elected representatives of a Band Council authorize an action. It is similar to a municipal by-law) was obtained. The Alexis Working and Adaptation Committees met on a regular basis over two years and through a process of consensus completed the research objectives.

Aboriginal ways of knowing including ceremonies, prayer, storytelling, circle theories and the recognition of people’s own life stories are the foundations upon which the adaptations were made. Where appropriate, the program was translated into the Isga language and a cultural activity/ceremony, chosen by community Elders, was added to each program module. The Isga language, also known as Stoney, is the ancestral language of the people of the Alexis Nakota Sioux Nation A community artist was hired to create culturally appropriate images that were committee member. The primary role of the Alexis Working Committee has been to oversee general operations of the project including funding, expenditures, timelines, and interpretation and presentation of research results. In addition, an Adaptations Committee was established. The role of this committee was to work specifically on program adaptations. Membership in the Adaptations Committee included community members and school personnel who were also the community representatives of the Alexis Working Committee and included one or more Elders at each meeting. There was also an open invitation for any parent of the school to attend a meeting of the Adaptations Committee at any time.

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Focus Groups
Following completion of the cultural adaptations and delivery of the program, two focus groups were convened: one with school personnel/community members who were actively involved in supporting or working with the program and another with Elders who contributed to the cultural adaptations, language translation and classroom delivery. All school personnel/community members and Elders who were directly involved in the adaptation or delivery of the program were invited to participate in a focus group. Focus groups were held in the school staff room during a time that was convenient for all participants. The school personnel/community member focus group guide (Appendix I) and the Elder focus group guide (Appendix II) were used to facilitate focus group discussions. Prior consent to record, transcribe and analyze the conversations was obtained from all focus group participants as per the University of Alberta’s ethical requirements. Data from each focus group was analyzed separately by two members of the Women and Children’s Health CBPR Group who also facilitated the focus group discussions. These independent analyses were then collectively reviewed and common interpretations and themes were identified and presented to focus group participants for feedback and validation.

Participants in both the school personnel/community member and Elder focus groups were asked to speak about their experience of either the adaptation process or delivery of the program, whether they felt that their knowledge and experience were valued by the research team, what they liked most and least about the process and how they felt about the program as it was delivered. Finally, they were asked if there were unanticipated challenges and benefits.

Public Health Agency of Canada Community Capacity Building Tool (PHAC-CCBT)
In 2007, the PHAC published the final draft of an evidence based Community Capacity Building Tool (CCBT) designed to document capacity building as it occurs in collaborative CBPR projects (http://www.phac-aspc.gc.ca/canada/regions/ab-nwt/downloads.html). The design and subsequent evaluation of the CCBT has been documented in detail. The CCBT includes 9 domains; (1) participation, (2) leadership, (3) community structures, (4) role of external support, (5) asking why, and (9) sense of community. Each domain has a number of indicator items (range 1–4, with a total of 26 items) and each item has 4
response options (just started, on the road, nearly there, we're there) and the opportunity to add contextual descriptive information. The contextual descriptive information allows for elaboration on why the response option was chosen and the unique conditions under which the project was operating.

The PHAC-CCBT was used to document changes in community capacity during the two years that the LST program adaptations were made and upon completion of delivery of the first level of the adapted program. Information was obtained from focus group discussions with community based researchers and Alexis Working Committee members. Response options (‘just started’, ‘on the road’, ‘nearly there’, ‘we’re there’) for each of the 9 domains were determined by consensus and subsequently mapped using bar graphs. Qualitative responses to each domain’s indicator item were recorded and transcribed. Emerging themes within and across years were studied in an effort to identify trends, relationships, consistencies and inconsistencies.

**Results**

**LST Questionnaire**

We obtained 17 consents from a total of 20 children in the grade 3 classroom. Of these 17 children, 15 were available for the pre-test and 11 of those 15 were available for the post-test. Due to the sample size we did not have the power to conduct statistical tests (e.g., repeated measures ANOVA or t-tests); instead we looked at descriptive statistics from the pre and posttests. On all of the summary scores from the LST questionnaire the majority of the children increased from pre to posttest. Specifically, the percentage of children whose scores increased from pre to posttest on each summary score was: 55% for overall knowledge, 55% for drug knowledge, 64% for life skills knowledge, 46% for drug attitudes, and 73% for life skills summary. Some questions showed a dramatic improvement. For example, on the question ‘there are good ways to use tobacco’, 27% of the children responded correctly on the pretest compared to 91% on the posttest. On the question, ‘smoking can cause skin to wrinkle’ 45% were correct on the pretest and 82% on the posttest. Finally, on the pretest only 55% of the children agreed with the statement ‘if someone wants you to do something you don’t want to do, there are many ways you can refuse’, as compared to 81% on the posttest. Thus, after having received only the first level of the 3 level, three year program the majority of children already showed an increase from pre to posttest summary scores. Although these results are descriptive and preliminary, they are congruent with previously published studies by Botvin and colleagues demonstrating positive effects of the LST program.17

**Focus groups**

Eight school personnel/community members and six Elders participated in two separate focus groups. Common themes emerged during the analysis and these are presented below. Throughout the discussions, there were repeated references to the personal and community benefits of adapting and delivering the program. The adaptation of the program presented challenges, including: pace, role confusion and overload, ceremonies, and language. Finally, participants provided recommendations for improving both the content of the program and its delivery. Direct quotes from the focus group participants reflect community investment in the program as well as frustrations and insights gained over the 12 months in which the program was adapted and delivered to a class of grade 3 students.
Benefits
The benefits of a program that is bringing culture and tradition back to the community were recognized at multiple levels, for the community itself, the school, and for individuals. For the school, the process of adapting the program was seen as valuable for ensuring sustainability of the program in terms of both its ongoing use in the school and its impact on students. Participants spoke of their work in the adaptation and delivery of the program as personally satisfying because they were fulfilling a personal commitment to preserve the Isga culture and work closely with Elders. For Elders themselves, the program gave them the opportunity to contribute to the development of youth in the community.

At the end of September remember we had a parent advisory meeting and the Chief was here and he said a few words, "We need to do something as a community ... to bring culture and tradition back for our kids." And I think this program will do just that; this is one good thing for our kids and for the future. (school/community focus group)

[By] going through this process of making it our own, it has enough meaning that I think it's going to continue to be used, because a really good program does not have any benefit if the teachers aren't teaching it in the classroom. We really should be doing this with all of our curriculum because that's where it becomes meaningful for our kids...because if it's not meaningful it's not going to stay with the kids, it's not going to make them feel valued...feel like they belong. (school/community focus group)

I was very interested in this program because of the Elders, being around the Elders and just getting to know them, and getting to know my wording, how it was spelled... it was very interesting. (school/community focus group)

I like this, myself, because someday I want these kids to be somebody. They lost their language, they're nobody.... And it will be us that put it together, that's another good thing. (Elder focus group)

Challenges
Participants in both focus groups discussed the challenges present in adapting the program. Challenges include: timelines for completing the work, work overload, and the complexity of translating English terminology into the Isga language.

School personnel/community members experienced stress as they worked to maintain congruency between externally imposed funding timelines and the progress of the adaptation process. A greater amount of time than anticipated was required for community members and Elders to reach consensus around cultural stories and how these stories might best inform adaptations to the program. This stress was exacerbated by cultural differences in the perception of time, differences that were noted by Elders. At the same time, the funding agency had specific deadlines and funding extensions that were compatible with the needs of the community were difficult to secure.

I am so driven by time and timelines...several times the Elders had to point out to me, "are you on a racetrack or what? We don’t work like that." They said Stoney people don’t work that way, we have to think about this and I had to back off many times. (school/community focus group)

Advancing the Fetal Alcohol Spectrum Disorder (FASD) Research Agenda
Participants also spoke about the challenge of taking on additional work and assuming new roles in the community. Alexis Nakota Sioux Nation is a small community with limited resources and the Elders, community members and school staff involved in the project were often contributing to the adaptations in addition to their existing professional obligations. Participants described the challenge as one between the time and energy required for professional responsibilities to the community and the added workload of participating in the program’s adaptation.

*I was getting frustrated because it took a lot of my time, my free time. I had no free time.... I like working with it, but it was just stressing me out.* (school/community focus group)

There was a shared commitment to integrate the Isga language in the program however the translation process presented challenges because this was the first time that this particular group of Elders had been asked to reach consensus in translating English words into the Isga language. The difficulty that Elders experienced in reaching consensus was an uncommon experience in focus group participants’ work with Elders. Focus group participants discussed the historical context for such an experience. The diversity of languages spoken historically by members of Alexis Nakota Sioux contributed, in part, to the challenge of reaching consensus. Further, the process of translation was understood as the opportunity for individuals to re-discover language that had been ‘lost’ as a result of the residential school experience.

*...one of the reasons why [translation is difficult] is maybe because of the different ancestors we come from – like Cree, Ojibway, Iroquois, Métis ... and how they pronounced the words might have influenced the words as they were spoken here. So, it doesn’t surprise me to hear that there wasn’t always consensus.*

(school/community focus group)

[Elders] were learning about their language as well. ... They were being reminded and they were re-learning some of their words that they had forgotten about. (school/community focus group)

**Recommendations**

Recommendations for the delivery of the program included: expanding the timeframe for the program’s delivery, enhancing parental involvement, suggestions regarding the inclusion of ceremony, and broadening Elder participation. An overarching recommendation was the need for increased communication with all community members about the program, its content and anticipated outcomes. Participants in both focus groups spoke about the importance of providing frequent updates to the community on the progress of the program’s adaptation and delivery. The knowledge obtained through this ongoing communication would provide a level of comfort for the students’ parents/guardians and the Elders about their participation in the program.

Those who participated in the delivery of the program agreed that the time allotted for its delivery was insufficient. In order to do justice to the inclusion of language and culture, lessons that were one hour in length in the original program require double or triple the time. Furthermore, the individuals who are delivering the program are community members so they need more support in delivering the program.
From a teacher’s point of view, I would say it definitely needs more time. I wouldn’t do it in one block; I would probably have more lessons over a longer period of time, not even in two weeks or not two a week, but one a week for a longer period of time, like maybe the whole year. (school/community focus group)

... the people facilitating [program delivery] are not teachers and the manuals are written for teachers. Teachers are used to following manuals and so some of things that [a teacher] might take for granted are not known by these facilitators so we realized that the next time we rewrite we will have to put in more points, more detail. (school/community focus group)

Parents were invited to participate in the training workshops in preparation for the program’s delivery and they consented to their child’s participation in the program. Building on this, focus group participants expressed a need for ongoing, in-depth communication with the families to support parents in following through with teachings of the program. As well, there was an expressed need for a similar program for the 30-45 year old age group in the community.

We should make it mandatory to have parent volunteers each week from the classroom ... have a two-day workshop with them and go through each lesson thoroughly before you implement it. So they know what’s coming up and at that workshop they could sign up for their volunteer day.   (school/community focus group)

The middle-aged group could benefit from this program [because] they never had these experiences now that their children are having. (Elder focus group)

Recommendations regarding the inclusion of ceremonies in the program were based on the reactions of both the Elders and the children’s families to the naming ceremony. Discussion during focus groups indicate the need for community Elders, parents and school staff to engage in discussions around the meaning and intent of a ceremony before it is delivered in the context of the program.

In our culture we don’t really have a formal naming ceremony and we got the Elders to do it and I was interested to see what was going to transpire and they came through with what we assumed was comfortable with them. ... but I think ... afterwards they kind of felt they might have offended the child or the parents. I think we really need to sit down prior to... (school/community focus group)

The adapted program’s attention to culture and language requires an Isga language speaker to participate in the program’s delivery in addition to an Elder. Participants in the school personnel/community member focus group spoke of the value of a team approach to program delivery that included two community members co-teaching the program, an Elder and the classroom teacher. The Elder assisted with any questions about culture, language, and ceremony and the classroom teacher assisted with any behavioral issues. Finally, participants envisioned the possibility of strengthening the role of the Elders in the community through this program.

Once we take and actually incorporate the wisdom and not only the words we immediately can send the children back to the people that are locally recognized as experts and helpers. So we are taking it beyond just a school program, we are taking the young and tying them into a system of support that is already in place in the community And I think that’s the biggest potential in adapting this [program] culturally, you can
incorporate this system of support and you can strengthen the role of Elders and people that heal. You provide positive role modeling by incorporating them directly. (school/community focus group)

**Public Health Agency of Canada Community Capacity Building Tool (PHAC-CCBT)**

Community capacity includes those attributes that empower a community to take action for the purpose of effecting social change and has been shown to be a proxy measure of community health and an important step towards self-determination especially in minority and marginalized populations. Unlike changes in health outcomes which may not be measurable for several years after the implementation of a community intervention, growth in community capacity can be documented longitudinally throughout the development of a community based research project.

Using the PHAC-CCBT we documented longitudinal growth in all nine areas of community capacity. The quantitative results are summarized in Appendix III. An indepth review of the quantitative and qualitative results have been published, and are available online (http://www.pimatisiwin.com/Issues/AllIssues.html).

**Summary**

Substance abuse and drug and alcohol related morbidity and mortality are disproportionately high in Aboriginal communities in Canada. Despite this fact, drug and alcohol prevention programs are not available to the majority of children attending First Nations schools. LST is currently the most evidenced-based drug and alcohol prevention program available in North America; however, it is a generic program and its effectiveness with Aboriginal children attending First Nations schools is not known.

The literature is clear that a prevention program is most effective when tailored to align with the values, beliefs, customs, and cultural context of the population where it is delivered especially when researchers and community members work in collaboration using a CBPR approach. In addition, when a target population receives the delivery of a program from trained community members, retention rates are higher as trust is more easily developed between the target population and community facilitators. Furthermore, as stated by Sanders “there is an ethical imperative” to ensure that interventions developed for the dominant culture do not negatively impact the cultural values, competence or language of the non-dominant culture where the program will be delivered. Culturally adapted programs have the potential to have a three-fold effect. First, those who participate are able to relate more closely to the curricula and therefore more likely to engage in the program. Second, a culturally adapted program can aid in the development of a stronger identity and cultural pride, which may, in turn, function as a protective factor. Third, a community involved in the adaptation and implementation of a prevention program is more likely to feel a sense of ownership and empowerment.

Based on findings from the current project, the benefits of a culturally adapted drug and alcohol prevention program were documented. Outcomes included: 1) positive changes in student participants’ drug and alcohol refusal skills, self-beliefs, and knowledge of the negative effects of drug and alcohol use, 2) ownership of and investment in the program by the community, 3) teaching approaches and activities that fit the learning contexts, worldviews and relationships of the community, 4) participation of...
Elders to ensure that learning activities reflect traditional ways of knowing and 5) longitudinal growth in community capacity. Information gathered by quantitative measures, focus group discussions and the PHAC-CCBT provide evidence for the relevance, importance, and benefits of employing a culturally adapted substance abuse prevention program with Aboriginal students attending a First Nations school. The program has the potential for implementation in other First Nations across Canada.

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References


The Effectiveness of FASD Programs on Outcomes of At-Risk Mothers, Families, and Parents with FASD
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Main Messages

• There are few FASD intervention programs available for at-risk mothers, families and parents with FASD. There are even fewer studies on the effectiveness of these programs. Systematic supports for evaluations of intervention mentor programs are vital and important to the work being done in the community.

• FASD is a complex disability that requires much support on a number of fronts, including prevention and intervention supports for women at risk of giving birth to a child prenatally exposed to alcohol, to affected individuals themselves, as well as families raising children and adults impacted by FASD.

• A retrospective analysis of Catholic Social Services’ FASD programs has demonstrated that the programs are successful in helping clients meet their needs and achieve their goals. Given the high prevalence of FASD, more programs such as these are needed throughout Canada, and the world.

• A higher proportion of prevention resources should be targeted at high risk populations. The Parent–Child Assistance Program (PCAP) has shown great success, and Canadian programs based on the PCAP model, such as First Steps, should be encouraged.

• Research and evaluation should be embedded into FASD prevention programs and services to allow for self-correction, continuous improvement, as well as better facilitation of formal research projects and knowledge dissemination.

• As FASD is a lifelong disability, there should be a commitment by government to provide seamless and equitable services across the lifespan of affected individuals.

• Community-based research is an essential component to strengthening communities and impacting positive social change.

• Dissemination of knowledge gathered and evaluated through community-based research projects allows for the removal of barriers that exist between funders, policy makers, agencies, community workers and the members of the community served by the organizations.

• Continued research on the effectiveness of FASD intervention programs is essential. Longitudinal studies are especially necessary to determine whether clients maintain their improvements long-term after exiting programs.

Executive Summary

Catholic Social Services’ FASD programs, as part of their case management practice, have been collecting data from each of their 3 FASD programs since their inception. Previous to this research collaboration, none of this data had ever been formally evaluated to determine the effectiveness these programs. Through our evaluation, it was determined that each of the programs helped clients decrease their needs and achieve their goals.

The Coaching Families program, which supports families parenting one or more children diagnosed with FASD, was found to have helped parents most significantly with needs in the areas of housing and transportation, family parenting and community development. All of the goal areas showed improvement, with the areas of parenting and resources showing the most significant growth. Caregivers in this program also self-reported having significantly lower levels of stress post-program, based on a Stress Survey completed before and after participation.
The Step by Step program provides assistance to parents with FASD who are parenting children who may or may not have FASD themselves. Clients in this program showed the largest improvement in the areas of abuse, social problems, housing and transportation and community resources. The program also helped clients achieve their goals most significantly in the areas of self-care and health, and self-reliance. Clients in this program were found to be facing multiple barriers in addition to their FASD, including mental health issues, past and/or present experience of abuse and addictions issues.

The First Steps program provides support to women who are at risk of giving birth to a child with FASD. The women in this program showed significant improvement in their needs in the areas of independence and financial issues, community resources and addictions problems.

The goals that showed the most significant improvement over the course of the program were parenting, self-care and health, and family planning. Comparisons between clients’ answers on the Addictions Severity Index (ASI) and Biannual Report were used to assess whether or not clients were able to address birth control issues and reduce substance use, as well as measure the number of subsequent pregnancies that clients had during their time in the program. Overall, clients showed a significant increase in regular use of family planning methods, including 21% of the study group obtaining tubal ligations. There were only a very small number of clients who gave birth to another child while participating in the program, and there was an overall decrease in welfare use.

Another significant finding is that clients in all three programs reported having overall very positive experiences with the programs. Clients were given anonymous satisfaction surveys to fill out and return to the program on a yearly basis and at closure. Data from these surveys showed that almost all of the clients felt that they were better off having spent time in the program, that they enjoyed what the program had to offer and that the mentor and the program helped them make significant improvement in their lives. Through this research project we were able to identify areas in which the programs are showing success, but also areas that need improvement. Because this was a retrospective analysis of data that had already been collected, we were limited by the programs’ own data collection procedures. One key finding was that some of the clients’ post-needs and goals measures were not being completed upon exiting the program, and thus could not be used in our study. Feedback was given to CSS about this limitation and there have been renewed efforts to fix this issue.

This research project also allowed for a more formal articulation of each of the programs. One reason this is so important is that many new FASD intervention programs are in the process of development across Alberta and Canada. Since Catholic Social Services’ FASD programs were among the first to start-up across the province and country, they are frequent hosts to others hoping to learn about development and implementation of successful FASD intervention programs. In addition, funding bodies and government agencies are demanding more empirical evidence on program effectiveness to determine future funding for programs. All of the results from this study were presented to CSS program mentors, allowing them to better understand why it is so important that they continue to do the work they do. The CSS staff reported that they greatly enjoyed receiving feedback about their work, as it is often difficult to observe or measure their successes with the at-risk mothers, parents and families affected by FASD that they work with.
Early Intervention Programs for Alberta’s Children with a Fetal Alcohol Spectrum Disorder (FASD): Characteristics of Service Delivery

December 31, 2008

This study was funded through the Alberta Centre for Child, Family and Community Research (ACCFCR) in accordance with their goal to identify and promote research that will guide policy decision-making and enhance service delivery programs for Alberta’s children.
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Executive Summary
Purpose of the Study
The purpose of this research was to describe the characteristics of early intervention programs for Alberta’s children age zero to 12 years with a FASD and their families. An attempt was made to identify those factors that facilitate program efforts, effectiveness, efficiency and adequacy, and those that positively influence the health status of the children and their families. The aim of this study was to facilitate beginning understanding of how services are meeting the complex health determinants of children with a FASD and their families; identify potential health disparities or gaps in services provided; identify facilitators and barriers to early intervention programs; and guide policy decision-making and enhance service delivery programs for Alberta’s children.

Methods
Design:
A non-experimental descriptive survey design was used to summarize essential characteristics of early intervention programs for Alberta’s children from birth to 12 years of age with a FASD and their families. A theoretically-based questionnaire was developed using an overarching framework for program evaluation in public health (Health Canada, 2001) and a framework for building a system of strategies to promote early childhood development (Federal/Provincial/Territorial Advisory Committee on Population Health and Health Security, 2003). Several models (e.g., health promotion model, and socio-ecological model) were used to organize the essential elements of the program (Hamilton and Bhatti, 1996; Stokols, 1996) including target population and need, expected effects, activities, resources, and stages of program development. The questionnaire was piloted in two early intervention programs, as well as reviewed by two experts in the field. The questionnaire predominantly used dichotomous questions, multiple choice questions and Likert-type scale questions in order to facilitate completion of the questionnaire by respondents.

Sample and Data Collection:
44 intervention programs in Alberta were identified and all were contacted. Only those programs that provided services to children under 12 years of age, provided intervention services defined as an action(s) or strategy(ies) that address core features of a FASD and specifically targeted children with a FASD were included in the study. 23 programs were identified that met these inclusion criteria. During the study, one program was terminated and another could not be contacted. The Directors or Supervisors of an identified program completed the questionnaire. Questionnaires were hand-delivered to local programs and were couriered to all other programs. A maximum of two reminder phone calls were made to help ensure completion of the questionnaire. 21 questionnaires were sent out; however one was returned as the program was not an intervention program. Of the 20 remaining questionnaires, 12 were completed and returned, a response rate of 60%.

Data Analysis:
A master coding scheme was developed for the closed-ended questions in the questionnaire and used to enter survey data into Statistical Package for the Social Sciences (SPSS) version 16. Data were entered by a statistical consultant and the principle investigator cross-checked 3 questionnaires (25% of the sample), identified using a random number table, for accuracy of data entry. An incorrect entry was made for the other category in reference to question #3 that was corrected; otherwise there was
complete agreement. Frequencies were generated for multiple-choice questions. For open-ended questions which generated a numerical response, data were not normally distributed even after log transformation; hence medians and inter quartile ranges have been reported. For 7-point Likert-type scale questions the negative scores implied the factors were barrier (scores of -3 associated with a strongly negative influence and -1 indicating mildly negative influence), positive scores implied the factors were facilitators (scores of 3 associated with a strongly positive influence and 1 indicating mildly positive influence), and zero implied no influence. Reported for each response were a frequency and percentage, as well as a median value. Descriptive statistics were used to highlight similarities and differences between programs. In instances where open-ended questions were used to elicit subjective responses, content analysis was used to objectively, and systematically identify themes that emerged in the written responses (Polit & Beck, 2008). The principal investigator conducted the content analysis.

Findings

Please refer to the report for findings. Key findings are presented in the discussion which follows.

Discussion

An initial perusal of the resource directories suggested that there are numerous programs, 44 in total, which attend to Alberta’s children age zero to 12 years with a FASD and their families. However, only approximately half provided services to children age zero to 12 years who are suspected of or have a diagnosis of a FASD. A little over 10 percent of the programs could not be reached and the remaining provided services to older children. During the time period between screening and mailing of questionnaire, which was approximately 14 months, one program was terminated, and another changed its name or contact information and could not be reached. Therefore, a challenge relates to maintaining accurate and updated information about programs, which provide services to Alberta’s children age zero to 12 years with a FASD, and ensuring this information is updated in a timely way every year.

Early intervention programs participating in this study serve Alberta’s children age zero to 12 years with a FASD and their families residing in 7 of the 9 regions as delineated by Alberta Children’s Services. Two regions most represented were Calgary and area (42%) and Southern Alberta (25%) and two regions not represented were North Central Alberta and North West Alberta regions. Given the lack of understanding about the true prevalence of a FASD and the geographical distribution of children age zero to 12 years with a FASD, as well a response rate of 60%, it is difficult to appraise whether appropriate program distribution exists in Alberta. Health care disparities defined as “the mismatch between need and access associated with membership in one socially identifiable and disadvantaged group compared with their nondisadvantaged counterpart” (Franks & Fiscella, 2008; p. 672) may be associated with geographical distribution of early intervention programs. Disparities associated with geography may create inequities in access and use of services among alcohol-affected children and their families who are a group already at risk. An important area for future study is the identification of factors that influence access and utilization of early intervention programs for alcohol affected children and their families who reside in Alberta.

Nine (75%) of the early intervention programs reported that the location of their program (i.e., setting) had a positive influence on facilitating their services; however the degree varied from mildly positive (17%), moderately positive (25%), to strongly positive (33%). Three (25%) indicated the location of their
program had no influence on facilitating their services. A program's ability to provide services and support health may be influenced by policy decisions, political mandates, funding, particularly cutbacks in funding (Raphael, Phillips, Renwick, & Sehdev, 2000). Funding sources were variable in that 6 (55%) were funded provincially and 5 (45%) were funded by multiple sources including provincial government (100%), federal government (20%), non-government agencies (20%), corporate sector (20%) and other such as fee for service, donations, and fund raising (40%). As well, the annual program budget differed; the median being $315,856 (quartile range of $97,345 to $500,000). Despite these differences, the degree of influence of financial support for program was rated to be strongly positive and moderately positive by 8 (67%) and 3 (25%) of early intervention programs, respectively. Only 1 (8%) early intervention program rated the influence of financial support for program to be strongly negative.

Early intervention programs varied in their rating of the degree of influence of the political climate (provincial and national) on facilitating the services of the program. The influence of the political climate on early intervention programs was rated as strongly positive by 2 (17%) program, moderately positive by 5 (42%), mildly positive by 2 (17%), no influence by 1 (8%) and moderately negative by 1 (8%). The findings suggest that it is important to explore the Directors or Supervisors perceptions of opportunities and challenges experienced by early intervention programs when examining characteristics.

Early intervention programs target multiple levels such as individual, community, society, and involve multiple systems (i.e., two or more service providers or community stakeholders). Although programs attend to multiple needs of affected children and families, few attend to all needs of children and families, 30% and 40% respectively. Two (22%) of the early intervention programs indicated that they provide the affected child ongoing support and three (33%) indicated that they provide families “continuous” or “ongoing” support. A majority of programs (75%) use a multidisciplinary approach. The multi-level, multi-strategy, and multidisciplinary approach described by early intervention programs is consistent with: a) the themes of the expected effects extracted from the data on missions, goals, and objectives, and b) the myriad of problems experienced by alcohol affected children and their families as highlighted in the literature. A multidisciplinary team should work together to attend to all needs of the child with a FASD and their families (Premji et al., 2004). Alcohol impacts functioning throughout the lifespan of an affected individual (Streissguth et al., 1994); hence early intervention programs should extend across the lifespan of the individual focusing on life-long management (Premji et al., 2004).

The eligibility criteria for affected children to enter and receive services were dissimilar across programs and suggested that some early intervention programs serve a more general population. One may postulate that differences in eligibility criteria may be related to maturity of program (Dick et al., 2003). However, the twelve early intervention programs have been operational for a median duration of 6.7 years; lower and upper quartile of 6 years and 9 years, respectively. Hence, duration of program may not account for differences in eligibility criteria noted across early intervention programs. How FASD fits into the mandates of these more general programs requires further exploration, as well as how eligibility impacts enrollment of alcohol affected children and their families.

Programs directing services to the child affected with a FASD also varied with respect to other characteristics such as particular family members targeted, number of programs offered, and their
length, activities, and process of determining priority areas of needs and referral. Program characteristics have been reported to be associated with client engagement (Broome, Flynn, Knight, & Simpson, 2007), outcomes, and health status of those enrolled in the program (Mukamel, Peterson, Temkin-Greener, Delavan, Gross, Kunitz et al., 2007). Early intervention programs reported that only 80 to 90% of both affected children and their families completed their program. The current study did not measure health outcomes nor assess health status of those enrolled in the program. A better understanding is required of the relationship between early intervention program characteristics and client engagement, and outcomes for the affected child and his/her family. Identifying key program attributes will help identify effective model(s) of care, as well help focus resources and services to attain specific outcomes (Mukamel et al., 2007).

Children with a FASD, as well as their families, are often affected by a myriad of difficulty. Early intervention programs attend to multiple needs of the child and family and have multiple strategies that are directed at multiple levels in multiple settings. Additionally, early intervention programs indicated that the care for children with a FASD and their families falls within the purview of many service providers or community stakeholders. How well these multifaceted programs are integrated within and between levels, settings, and strategies, requires evaluation. Explicating an evidence-based conceptual framework to guide the development of such multifaceted programs for Alberta Children’s age zero to 12 years with a FASD and their families will facilitate appraisal of effectiveness.

An organization’s effectiveness may be enhanced by their capacity to engage in research (Majchrzak, 1982); however most measures of research capacity were rated by early intervention programs as either fairly poor, no influence, or fairly good. Academic preparations (e.g., higher degrees such as Doctor of Philosophy) or research-related education was identified as a barrier to developing research capacity. Increasing motivation to undertake research, and strengthening the culture and support for research may positively influence a programs capacity to engage in research thereby improving effectiveness.

Early intervention programs focus predominantly on “downstream” interventions directing activities or strategies toward the care of the affected child and their families (Bekemeier, 2008). Even community strategies tended to focus more on provision of support to parents (e.g., respite program), training of health professionals, caregivers, and hosting conferences. At the community level some strategies included health promotion programs about FASD and were directed at the community or specific groups (e.g., post-secondary classes) and were thereby classified as “midstream” interventions (Orleans, Gruman, Ulmer, Emont, & Hollendonner, 1999). However these type of interventions were not a dominant theme in the findings (i.e., mentioned by only 2 early intervention programs). “Upstream” interventions entail directing efforts to improve population health by addressing underlying social determinants of alcohol exposure during pregnancy through changing national public policy, shaping social norms, etc. (Bekemeier, 2008; Orleans et al., 1999). These structural interventions were not evident in the data shared. For instance, none of the early intervention programs indicated formal involvement at the political system (e.g., government) level. A successful population health perspective requires implementation of downstream, midstream, and upstream interventions.
Conclusions
Overall, early intervention programs for Alberta’s children from birth to 12 years of age with a FASD and their families are multi-level and multi-system, they differ in key elements of program (e.g., eligibility criteria, number of programs, and duration of program). At present we do not have an understanding of the essential attributes of early intervention programs. Early intervention programs need to implement midstream, and upstream interventions to promote a population health perspective. Developing research capacity was identified as a need by respondents and may be important to improving effectiveness of programs.

Recommendations for Healthcare Policy Makers
- An accurate resource directory should be developed and maintained so that it is easy to identify early intervention programs which are specific to children age zero to 12 years with a FASD.
- Create a provincial strategy for early intervention programs for children age zero to 12 years with a FASD.
- Early intervention programs should implement downstream, midstream, and upstream interventions and appropriate resources should be allocated to facilitate this.
- To enhance effectiveness of early intervention programs, develop research capacity within these programs.

Recommendations for Healthcare Researchers
- Identify appropriate means (e.g., standard definitions, methodologies, surveillance systems) to determine the true prevalence of a FASD. Mapping the distribution of children age zero to 12 years with a FASD against where early intervention programs are currently located, will enable identification of service delivery gaps (e.g., no programs or too few programs to meet the needs children age zero to 12 years with a FASD).
- Identify the current demand for services by children with a FASD and their families, and determine the extent to which existing early intervention programs are able to meet these demands.
- Explicate an evidence-based conceptual framework to guide the development and evaluation of an integrated multifaceted early intervention programs for alcohol-affected children and their families who reside in Alberta.
- Evaluate how well current multifaceted early intervention programs are integrated within and between levels, settings, and strategies.
- Develop a better understanding of the facilitators and barriers to delivery of service by early intervention programs as this enable identification of strategies to strengthen existing early intervention programs.
- Identify factors that influence access and utilization of early intervention programs for alcohol-affected children and their families who reside in Alberta.

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The impact of therapeutic respite care on young children with special needs and their caregivers

Final report prepared for the Alberta Centre for Child, Family & Community Research Sept 16, 2009
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This final report reflects the interpretation of the study findings by the report preparers, John D. McLennan, Liana Urichuk, Ashley Farrelly, and Emily Hutcheon. All points may not be agreed upon or endorsed by all the team members, participants, or funders.
MAIN MESSAGES

- Respite care is a valued service by parents struggling to raise children with special needs.
- Respite care can provide a temporary break for the parent.
- Whether respite care provides more than a temporary break is not evident.
- Respite care alone may not be adequate to reduce the chronic stress levels experienced by parents raising children with special needs.
- Respite care alone may not be adequate to improve child function.
- Linking children and families to additional needed, evidence-based, services and interventions may result in greater improvements in parent stress and child function.
- Further evaluation is required to determine the optimal type and intensity of respite services for different populations of families with children at risk.
- Needs of children prenatally exposed to alcohol and/or with fetal alcohol spectrum disorder (FASD) and their families overlap substantially with the needs of other children and families with special needs. Children with FASD and their families should be able to be accommodated within high quality respite services along with non-FASD children with special needs.
- Eligibility for respite services should be based on the extent of need for such versus a child’s diagnostic category.
- Achieving satisfaction with services should not be interpreted as a proxy for improved functional outcomes for child and family. The latter needs to be specifically evaluated.
- It should not be assumed that well-intentioned services will necessarily achieve their stated objectives. There is a continued need for an extensive evaluation of many of the interventions and support services directed towards children and families throughout Alberta.
- A partnership between researchers and community agencies is a viable structure for evaluating real-world services. However, significant start-up time should be built into these collaborations to increase the likelihood of success. There also needs to be recognition of the potential competing demands between research rigor and service flexibility. While compromise is appropriate in some situations, excessive compromise can undermine the research, service or both. Finally, within such partnerships, the lead researchers should be external to the service process to increase the likelihood of an objective and dispassionate evaluation.

EXECUTIVE SUMMARY

Objective

Respite care for families with children with special needs is a desired service given the demands of child rearing and potential for burnout. The provision of respite care holds out a promise for aiding families by giving them a break which may lead to reduced stress and improved function. Respite services are often not evaluated to determine whether they achieve these aims. It cannot be assumed that all well-intentioned services will automatically achieve said goals. Evaluation provides the potential for better understanding whether current respite services are helpful and, if not, what might be changed to improve their effectiveness. The aim of this project was to determine whether a new centre-based respite service for families of young children achieved their desired goals for the children and families served.
**Background**
A not-for profit respite provider, Kids Kottage, received a special grant from the McDaniel Family Foundation and Minerva Foundation to develop a new respite service for families with young children with special needs. There was a particular interest in developing a service that would be suitable for children prenatally exposed to alcohol and/or with fetal alcohol spectrum disorder (FASD). Kids Kottage entered into a partnership with Elves Special Needs Society to deliver this new centre-based respite service in Edmonton. The grant was contingent upon an external evaluation component which was funded by the Alberta Centre for Child, Family and Community Research.

The resulting centre-based respite service provided six hours per week of respite for each participating family for a ten month period. To be eligible, children needed to be between three and eight years of age and to demonstrate some emotional/behavioural problems and/or have been prenatally-exposed to alcohol. During the respite periods, children participated in a broad variety of activities at the centre including physical activities, play centres, and social skills activities with close management by experienced family providers. Parents were free to do as they chose during these periods.

**Key Findings**
As revealed through qualitative interviews, parents tended to describe experiencing multiple benefits from the respite service including a sense of a break, more time for family and other activities, and improvements in their child’s behaviour. Despite these positive endorsements, there was little change noted on standardized measures quantifying parent stress and child mental health function collected at multiple time points. Though seemingly discrepant, it is important to note that the qualitative interviews and standardized quantitative measures were not necessarily measuring the same things. It is interpreted that parents did in fact experience a temporary sense of a break, a key desired impact of respite services. However, experiencing periods of temporary breaks may not have been adequate to reduce chronic stress. In particular, it was noted that a substantial portion of the chronic stress, as captured by the standardized measure – the Parent Stress Index, was driven by parents’ experience of substantial challenging behaviours of their children (which was also indexed by the child mental health measure). Although the respite service provided a temporary break, the parent still needed to face the challenging behaviours outside of respite time, which of course is the majority of the time. As respite is not known to improve child function, it may not be surprising that we did not find substantial improvements in child behaviour or in the likely associated levels of parent stress.

It is suggested that if the aim is to tackle a reduction in parent chronic stress and/or improve child function, then other more targeted services are required beyond respite. Linkage to evidence-based interventions for addressing challenging child behaviours may lead to greater inroads in these domains. This is not to argue that respite is not helpful or necessary. The point is that it is not enough to simply provide respite in situations where there is chronic stress and/or significant challenging child behaviours. That said, respite services do need to demonstrate that they are achieving their stated goals, whether it be the provision of a temporary break or otherwise. Presumably not all respite services are beneficial to those using them. Further work is needed to more clearly articulate and measure anticipated benefits from the variety of respite services currently provided in Alberta.
Methodological Details
The core of the study was a pre-post examination of parent stress and child mental health status of families participating in this new respite service. This was accomplished by having parents complete a standardized measure of stress (the Parent Stress Index-Short Form) at multiple time points. Child mental health status was primarily measured using the Strengths and Difficulties Questionnaire which was completed at similar points in time by both the parent and respite providers.

Other components of the study methodology included exploratory qualitative interviews to better understand the parent experience of the respite service as well as perspectives of staff. A small comparison population of parents seeking short-term, ad hoc respite (from a different respite provider) was also recruited to better understand the pattern of changes of children and families outside of the specific respite service under study. Recruitment and retention of the comparison sample was quite low, limiting the extent to which patterns could be determined. However, the data provide a preliminary indication of outcomes for families seeking respite care and changes over time, and provide some degree of an index to contrast the pattern of findings of the respite service under study.

Limitations
Some caution is required in interpreting the study results without qualification for practice and policy implications. No single study provides definitive information to accurately inform practice and policy, which would be more appropriately informed by a series of studies. Unfortunately relevant methodologically robust studies on this topic are few in number. There are several cautions we would flag for this particular study. First, the participants in this study represent a relatively small and select population which opens questions as to how far one should generalize the results from this population to other families seeking respite services. Second, we only examined one type of respite care, i.e., a centre-based program offering a certain number of hours per week for ten months. Other forms and intensities of respite services may result in different outcomes. Third, though we chose sound measurement scales to try and capture the hypothesized benefits of this service, no measurement scale is perfect, nor captures all possible benefits. Finally, we did not use an experimental design to examine this respite service. A randomized control trial (RCT) would have been the most rigorous design for determining the efficacy of this intervention and could have provided more definite results. However, this would have been difficult to accomplish within this particular situation given the short lead time prior to launching the study and the evolving nature of the new service. To properly employ a RCT, the services would have needed to be clearly established prior to beginning the study.

Suggested Next Steps
Further evaluations of respite services for parents of children with special needs are clearly needed. Building in the most rigorous evaluation design possible within real-world service settings will increase the chances of producing usable findings to inform practice and policy. Variation in respite services may be incorporated in these evaluations to maximize learnings. For example, providing different intensities and/or types of respite may provide more information as to what works best for whom. In addition, linking families seeking respite services to other services is likely required if the intent is to reduce chronic stress and improve child outcomes. Explicit efforts to link families to evidence-based treatment interventions could then be built into the evaluation design.
Service use and needs of families with children seen through FASD speciality clinics in Alberta*

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We first would like to thank the participating families from the Lakeland Centre for Fetal Alcohol Spectrum Disorder, Alberta Children’s Hospital FASD Diagnostic Clinic and Renfrew Educational Services for sharing their time and experiences with us. In addition we would like to thank staff at these same centres who helped facilitate this research process. Several research staff were involved in completing this study including Susan Huculak (project coordinator), Michelle Caza, Ashley Farrelly, Trish Longair, Jenna Doig, and Dr. Mary Perry Core funding for this project was provided by the Alberta Centre for Child, Family and Community Research. A supplemental grant was received from the Canada Northwest FASD Research Network. The Alberta Heritage Foundation for Medical Research and the Canadian Institutes of Health Research provided research salary award funding to the principal investigator, Dr. John McLennan, during the period of this study.

Disclaimer
This final report reflects the interpretation of the study findings by the report preparers, Susan Huculak and John McLennan, and all points may not be agreed upon or endorsed by all the team members, participants, or funders.
Main Messages

Needs of children and families seen through specialty Fetal Alcohol Spectrum Disorder (FASD) clinics vary substantially. Though this may partly be a function of differing manifestations of alcohol exposure, it is also likely that this is a function of differing patterns of other risk factors and life situations. Focusing solely on alcohol exposure in utero and FASD may miss other important domains contributing to these children’s struggles.

Mental health symptoms and associated impairments are frequently found in referred children evaluated through FASD clinics. These difficulties may persist without access to effective treatment. Standardized mental health screening and assessments should be integrated into FASD evaluations and, where needed, linkages should be made to evidence-based mental health treatments.

Though mental health treatments were some of the most frequent services received by the participants, they were not received by all children with high levels of mental health symptoms. In addition, some of those receiving services likely were not receiving optimal or evidence-based treatments. Though the latter was not a specific component of this investigation, we know from other studies that a number of offered child mental health services are not evidence-based or effective.

Service experiences and service needs of participating families varied substantially. Though part of this variation is a function of the differing needs of the children, it may also be a function of the availability and accessibility of desired and effective services.

The need for additional services and problems with current services identified by participating caregivers were very similar to those of families with children with other special needs. This suggests that there is likely more commonality than difference shared by families with children with FASD and families with children with other special needs, at least as it pertains to services. This finding also points towards systemic gaps in service delivery in Alberta for children with special needs rather than necessarily unique deficits in services for families with FASD.

Executive Summary

This research study aimed: (1) to determine the follow-up service receipt patterns of families whose child had been assessed by a fetal alcohol spectrum disorder (FASD) clinic in Alberta; and (2) to identify experiences of these families in their attempt to obtain services and supports for themselves and their children. Within this inquiry we focused specifically on mental health difficulties and services as mental health difficulties are particularly common co-morbid problems in clinical populations of children with FASD and likely account for many of the difficulties these children have.

FASD is an umbrella term used as a short-hand to refer to one or more of several diagnostic terms used for disorders that are a function of prenatal alcohol exposure and include diagnoses such as fetal alcohol syndrome (FAS) and alcohol-related neurodevelopmental disorders (ARND).
What this study found...
About three-quarters of the participating children were reported to have high levels of mental health difficulties at both interview points. No overall net improvement in mental health problem status was observed for this group of children between the two time points (though there were individual changes). This is of particular concern given that this suggests persistent difficulties over a substantial time period for a population that is already linked with the formal service sector. It must be underscored that this does NOT mean that mental health difficulties for this population are not responsive to treatment. At least part of the problem is that some children and families were not receiving mental health services. It is also highly likely that some of those who were connected to services were not receiving effective, evidence-based interventions. Though the evidence-base of the services received was not a direct focus of this study, other studies have noted substantial research-practice gaps in mental health services for children. Among the key service categories we examined, 77% of families received at least one service in the past year, but many (nearly ¼) did not. The services reported most were those aimed at the child and were typically medications for the treatment of attention-deficit/hyperactivity disorder. Thirty-nine percent of the caregivers reported using at least one caregiver-related service, mainly in the form of respite. Thirty-three percent of caregivers reported using services aimed at the whole family such as family therapy. The table to the right displays a breakdown for specific services by target group.

The following are some of the key themes raised by caregivers in the second interview with regard to their experiences getting services:

- Most of the concerns and needs for services identified by caregivers as most salient for addressing their children’s difficulties were not FASD unique difficulties. The most common areas of need raised were to address (i) specific mental health problems, most typically

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This study in brief...

**Who?** Caregivers of children recently assessed at one of three fetal alcohol spectrum disorder (FASD) speciality clinics in Alberta. A total of 48 children (43 caregivers) were recruited out of a possible 142.

**What?** Caregivers participated in up to two telephone interviews following their original FASD assessment. The first interview, about 12 months after their FASD assessment, asked about services received by families using a structured interview. The second interview, about 12 months later, asked open-ended questions about needs and experiences with services received for the child and/or the family. Both interviews also identified the current mental health status of the child.

**Why?** We wanted to determine what mental health difficulties these children were having, whether their difficulties were changing over time, and the kinds of needs and experiences associated with service receipt the families of these children were having.

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Summary of service use as reported by caregivers (n = 43)

<table>
<thead>
<tr>
<th>Target Group</th>
<th>Service Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child - aimed</td>
<td>Psychotropic medication</td>
<td>49%</td>
</tr>
<tr>
<td></td>
<td>Counselling or play therapy</td>
<td>33%</td>
</tr>
<tr>
<td>Caregiver - aimed</td>
<td>Respite</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>Parenting support</td>
<td>21%</td>
</tr>
<tr>
<td>Family - aimed</td>
<td>Family therapy</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>In-home support</td>
<td>16%</td>
</tr>
</tbody>
</table>
associated with symptoms of attention deficit/hyperactivity disorder (ADHD) and/or behaviour
difficulties and/or (ii) life skills development, the latter which was most typically related to social
skills difficulties. The area of stated need in life/social skills development was a particular concern
vis-à-vis older youth and young adults.

• **The caregivers’ own needs** for services identified as most salient were a preference for familial,
friend, and particularly other FASD caregiver affiliations over more formalized and professional
forms of support. Many caregivers spoke highly, for example, of FASD parent mentorship programs
and parent support groups. In contrast to the non-FASD specific need orientation for their children,
these caregivers frequently appreciated being in the company of others knowledgeable of FASD,
typically for reasons such as to learn from others’ experience, to feel ‘understood’ and supported,
and to avoid feeling judged.

• Despite a clear need for services, multiple gaps and barriers to services were identified by caregivers
that impeded their success in securing services for themselves or their children. Additionally, several
caregivers alluded to experiences or fears of stigmatization associated with the FASD label as a kind
of barrier that impinged on their comfort with presenting themselves (or their children) into settings
where these attitudes may be experienced.

**Our conclusions and recommendations ...**

Though families were seen by specialty clinics within the formal health care sector, gaps appear in the
receipt of mental health services, i.e. services that should be accessible within the broader health system.
Greater access to mental health services may help reduce the persistent high levels of difficulties
experienced by these children. However, particular attention must be paid to the effectiveness of
received services. The following are suggested to providers and policy makers who may be involved with
service planning for populations of children with FASD and/or their families:

• Given the high rates of mental health difficulties in clinical populations of children with FASD,
clinics evaluating children for possible FASD ought to include standardized mental health
assessments. This should include a specific assessment for ADHD symptoms and behavioural
disorders.

• The systematic identification of co-morbid mental health problems is not adequate in and of itself.
Children with significant mental health problems need to be linked to evidence-based interventions
to address these problems. There are some popular beliefs about the ineffectiveness of evidence-
based mental health intervention for the FASD population. These beliefs are NOT based on any
empirical studies that we have been able to identify.

• Services and supports in priority functional areas, especially among youth and young adults,
should be offered or expanded. There is a particular call for work on life skills development
including social skills.

• Services and supports allowing caregivers to connect with other caregivers of children with FASD
(or similar complex difficulties) should be offered or expanded. These could occur across a variety
of formal and informal settings such as parent mentorships, online discussion forums, or support groups. Of note, aspects of this type of approach have been implemented elsewhere with reportedly promising results, for example in British Columbia with the “Key worker and parent support program” following a province-wide prioritization of life-long support to families affected by FASD.

• It is suggested that providers and policy makers incorporate the following topics into their discussions about client care and program development:
  • The potential stigmatizing effects associated with the “FASD” or “brain injury” label tied to the offering of services to either children with FASD or their caregivers, and
  • The balance of developing and offering services deemed unique for children with FASD in contrast to services based on need and guided by the child’s individual pattern of specific co-morbid difficulties.

Some final comments...
There are some limitations to this study. First, the study sample represents a subgroup attending FASD speciality clinics and may not be generalizable to a broader population of children with FASD in Alberta or beyond. Given that it is a clinical population, the rates of mental health difficulties are likely higher than within a broader population. We would also predict that the broader population has less connection with services. Second, the results from this study were based on parent-report information only, and should be interpreted as such. Though parents provide an essential perspective, obtaining multiple perspectives (e.g., from teachers, children, providers) would provide a more comprehensive picture. Third, this study did not include a comparison group which would have helped better identify if the experiences highlighted here were substantially different from those of caregivers with children with other special needs. Despite these limitations, the above findings can provide some direction for service reform, in concern with other studies, with the aim of improving outcomes for these children and their families.
Measuring Common Outcomes for FASD Intervention Programs

What do quality of life, self-efficacy, family functioning, hope and social support have in common? Researchers, policy makers and parents/caregivers think these are important outcomes that could help us better understand the impact of interventions for children and families. But how can we measure things like quality of life? It turns out there are many instruments that measure quality of life, family functioning, hope and social support. Some are easier to read and score, some are shorter, some have been tested more for accuracy and precision, and some cost less. After identifying 61 instruments and carefully reviewing the instruments for things like readability, length, reliability, validity and cost, only a third of the instruments were brought forward to be considered by a gathering of researchers, policy makers, and parents/caregivers in 2007.

Parents were asked how relevant the instrument was to their needs and how they felt about the length, language, and tone. Decision makers were asked to consider the burden on staff and clients should the instrument be routinely completed and if findings from the instruments would be relevant to the decision making process. Researchers were asked to discuss the psychometric properties (reliability, validity, etc.) of the scale, its value to research and their experience with the instrument. At the end of the meeting, the people at this gathering recommended the short-list of instruments below because they felt these instruments were most appropriate for future use in research, policy, and practice.

Why Measure the Same Outcomes with the Same Tools?
If programs measure these outcomes using the same instruments, they will be able to measure their achievements against things that are important to stakeholders, such as decision makers and parents. Using these measures also enhances the capacity of intervention programs to become involved in research. By measuring key outcomes in interest in the same way, interventions can also learn more from each other, knowing that they are measuring the same things.

### Quality of Life
- **Family Quality of Life Scale**
  - 25 questions to measure family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support.
  - Free of charge: www.beachcenter.org
  - SF8, SF12, or SF36: SF8 - 8 questions, <5 min.; SF12 - 12 questions, 5 min.; SF36 - 36 questions, 10 -15 min.
  - Measures health-related quality of life.
  - Charge for use: wwwwsf-36.org

### Self Efficacy
- **Psychological Empowerment Scale**
  - 32 questions to measure attitudes, participation (formal & informal), and skills and knowledge.

### Family Functioning
- **Family Functioning Style Scale**
  - 26 questions to measure commitment, cohesion, communication, competence, and coping, 8-10 min. Charge for use of most recent version: wbpress.com (Free of charge for older versions online or in one of the following books: Enabling and Empowering Families or Supporting and Strengthening Families.)
  - FAM III or FAM Brief: FAM III – 134 questions, 20 min. FAM Brief - 5-10 min.
  - Measures family health, relationship with other family members, and functioning within family.
  - Charge for use: wwwwi-r-p.ca

### Social Support
- **Family Support Scale**
  - 18 questions to measure informal kinship, spouse/partner support, social organizations, formal kinship, and professional services, 5 min.
  - Charge for use of most recent version: wbpress.com (Free of charge for older versions online or in one of the following books: Enabling and Empowering Families or Supporting and Strengthening Families.)

### Hope
- **Children’s Hope Scale**
  - 6 questions to measure hope in children 7 to 17 yrs old; <5 min. Free of charge: http://jpepsy.oxfordjournals.org/cgi/reprint/22/3/399

### Perceived Social Support Scale
- **PSS-FA**
  - 20 questions on PSS-FA to measure perceived family support.
  - Free of charge.

This project was supported by The Centre and the Canadian Northwest FASD Partnership
Exploring Pharmacists’ Role in FASD Awareness, Prevention and Intervention (2009)

The Centre collaborated with the Ministry of Children and Youth Services, the Alberta College of Pharmacists and the Faculty of Pharmacy at the University of Alberta to develop a survey to gauge Pharmacists’ level of interest in learning more about FASD and participating in awareness in prevention efforts. Pharmacists, the most accessible health care providers were targeted as a service provider group who may join the FASD prevention efforts because they consider their clients’ overall health and treatment options. In addition to being medication experts, pharmacists are a valuable resource for advice on non-prescription medications, natural health products, and healthy living.

The Centre contracted the Population Research Laboratory (PRL) at the University of Alberta to conduct the web-based survey which was distributed to 3400 practicing Pharmacists in Alberta. Of the 566 respondents, approximately 75% felt they could benefit from training in FASD awareness, treatment and patient education, and indicated willingness to distribute awareness and prevention materials to clients in their communities. More than half of respondents were interested in participating as a community resource in FASD prevention in the areas of referral, awareness and counseling.

Results of the Pharmacists’ On-line Survey

The Government of Alberta, as part of their FASD 10-year Strategic Plan (2008) are utilizing these findings to engage pharmacists to play a role in FASD awareness and prevention in their communities. The knowledge mobilization strategy, Engaging Alberta Pharmacists in FASD Awareness and Prevention Efforts is currently underway as described on page 6 and 7 of this compendium.

FASD Studies Currently In Progress

Fetal Alcohol Spectrum Disorder Practice Standards for Children in Care of Alberta Children and Youth Services (Investigator-Driven) Grant Holder: Dr. Dorothy Badry (PI)

This research is under way and a final report will be available upon study completion (April 2011). The following is an overview of proposed activities.

Objectives

The purpose of this project is to examine the impact and efficacy of specific case management practice standards for children with Fetal Alcohol Spectrum Disorder (FASD). Practice standards developed in Region 1 (Lethbridge) of Alberta Children’s Services in 2003 addressed the increased need for enhanced case management for children with FASD deemed to have unique and complex needs that exceed current practice standards within Children’s Services.

Research Questions

This study is attempting to answer two key questions. First, what is the impact of the FASD Practice Standards for the population of children in care, for those case workers implementing the standards, and the care giving network of foster parents providing care? Second, do the Practice Standards result in better outcomes; for example, reduced risk behaviours, school absences, and increased placement stability, for children impacted by FASD?
Key Findings
Key findings are not yet available but the research team is hypothesizing on what they expect the findings will be.
• There will be significantly lower number of placement disruptions and risk behaviors for children in the pilot group than for those in the comparison group.
• There will be a significantly higher perceived quality of foster parent-child relationships in the pilot group than for foster families in the comparison group.
• The provision of increased respite care will be associated with reduced placement disruption and risk behaviors.
• Worker contact with foster homes and the quality of foster parent-child relationships will have a positive correlation.

Study Progress
A qualitative analysis of Regions 1, 7, 9, and 10 (Lethbridge, High Prairie, St. Paul, and Fort McMurray, Alberta) took place over the fall of 2009, but further analysis is still taking place.

The recruitment method used for the purpose of this inquiry was a quasi-experimental matched comparison group design. As of October 31, 2009, 101 cases were included in the pilot group while 128 cases were included in the comparison group. Data collection continued for each child in the pilot site until June 30, 2010, and continued in the comparison site until December 31, 2010. The interim study results will be presented and discussed at The Centre hosted FASD Community of Practice Symposium on November 30, 2010. The presentations will be webcast and available for future viewing on The Centre’s website.

Developing a Collaborative Intervention for Children with Fetal Alcohol Spectrum Disorder: A Grassroots Approach (Seed Grant) Seed Grant Holder: Dr. Jacqueline Pei

This research is under way and a final report will be available upon study completion (April 2011). The following is an overview of proposed activities.

Objectives
The overall goal is to develop a collaborative systems level intervention that informs how the educational system goes about meeting the needs of individual students with FASD and their teachers. To identify successful and best practices for intervention, it was first necessary to undertake a period of exploration and information gathering.

Research Question
This research will attempt to answer how the educational system can best meet the needs of, as well as provide a nurturing environment for, students with Fetal Alcohol Spectrum Disorder (FASD) at the school level.

Knowledge Transfer Grants
Knowledge Transfer Grants are $5,000, one year awards intended to support activities that move research evidence into the hands of non-academics to inform policy and practice decisions and
ultimately improve the well-being of children, families and communities. Previous projects include distribution of information about study outcomes to community stakeholders, preparation of educational resources, and the development of policy briefs and materials for service providers.

The following are examples of products created through Centre supported Knowledge Transfer Grants.

**Executive Functioning in Children with FASD (2006) Carmen Rasmussen, PhD**
This knowledge transfer grant resulted in the production of an executive summary on this research study as well as a pamphlet highlighting the research findings for parents and caregivers working with children diagnosed with FASD. The executive summary and the pamphlet are available on the Centre’s website at www.research4children.com. The knowledge transfer grant also allowed for presentation of the research results at two conferences and for consultations with community groups to ensure that the research results were shared.

**Mathematics and Working Memory Development in Children with FASD**
**A Handbook for Educators (2006) Carmen Rasmussen, PhD**
This knowledge transfer grant resulted in the production of a handbook titled: “Mathematics Instruction for Children with Fetal Alcohol Spectrum Disorder: A Handbook for Educators.” The information and recommendations in the handbook was from a critical review of research on executive functioning (EF) in children with FASD and a study examining the profile of EF deficits in children with FASD.

**Target Audience and Intended Outcome of the KT Activities**
The handbook for educators covers mathematical learning deficits and development processes of children with FASD, and presents strategies to overcome these deficits and improve the classroom environment.

**Key Findings**
The handbook contains information specific to teaching children with FASD, but also contains information on teaching children with math difficulties in general. Below is a sample of findings found in the handbook taken from the research review.

- Considerable evidence indicates children and adolescents with FASD have specific deficits in mathematics and primarily arithmetic.
- Prenatal alcohol exposure appears to have a precise negative affect on mathematics abilities despite the IQ level of the individual.
- Children with math intervention show more improvements in math than children not receiving math intervention.

**Considerations for Service Providers, Administrators, and Policy Makers**
Based on the results from this study, the researchers suggest considerations for program planning.

- Before teaching children with FASD, educators should understand the child’s strengths and weaknesses; make a plan based on his or her needs; evaluate program effectiveness; and seek a classroom aid if the child still has difficulties.
• Allow the use of calculators to develop a child’s positive feelings about math and teach them higher-level problem solving strategies.
• Children with math deficits should receive more time on tests and assignments.

**Future Research:**
More research is needed to
• examine the long-term efficacy of mathematical intervention, such as the most appropriate duration of such a program;
• uncover whether such positive benefits from math intervention can be observed in group classroom settings; and
• determine why children with FASD have such deficits in mathematics and what areas of mathematics are most difficult for these children. This will inform instruction modification and intervention tailoring to improve math skills.

**Assessment of Cognitive Processing in Children and Adolescence with FASD: A Promising Alternative to Traditional IQ Tests (Knowledge Transfer Grant) (2006)**

Final report prepared by: Dr. Janine Odishaw

**Knowledge Transfer Activities**
The grant resulted in the production of a(n)
• policy brief titled: “Summary Information Regarding Criteria for Determining Funding for Adults with Fetal Alcohol Spectrum Disorder (FASD)”. The policy brief summarized key points from a study exploring the benefits of using the Cognitive Assessment System (CAS) to assess executive functioning (EF), attention, and other cognitive processes;
• presentation of the findings at local and international conferences on FASD
• executive summary (highlighted below) of the findings from this study for The Centre’s website and for distribution throughout Alberta.

**Purpose of the Study**
Current policies across Canada, the United States, and elsewhere throughout the world remain heavily reliant on IQ scores when determining funding eligibility for persons with developmental disabilities. These policies apply to individuals with Fetal Alcohol Spectrum Disorder (FASD) despite research which points to the limitations of traditional IQ tests at predicting adaptive skills and everyday functioning of persons with FASD. Deficits in executive functioning (EF) are thought to underlie many of the real-life problems faced by persons with FASD (Connor, Sampson, Bookstein, Barr, & Streissguth, 2000).

The limitations of IQ tests at accurately predicting adaptive functioning may be, in part, a function of the failure of some IQ tests at adequately measuring EF (Pennington & Ozonoff, 1996). The current study explored the benefits of employing the Cognitive Assessment System (CAS; Naglieri & Das, 1997) to assess EF, attention, and other cognitive processes in order to (a) better predict adaptive outcomes for persons with FASD, and (b) provide more meaningful direction for remediation.

The findings of this study suggest that even when EF is included in how one defines and measures intelligence, an overall IQ score does not adequately predict how a person with FASD functions in everyday life. While the overall full-scale IQ scores were not predictive of adaptive behaviour, two of the...
CAS component scores were predictive of parent-rated adaptive behaviour.

Rather than relying on an overall IQ score when determining funding eligibility for adults with FASD, policy makers should consider the use of other, more EF-related cognitive tests, when deciding upon service provision for this population. The Planning Component of the CAS offers a measure of EF that might be used in a battery of cognitive tests.

When comparing the finding of moderate correlations between the WISC-IV FSIQ and the ABAS-II Global Adaptive Composite in the standardization sample (Wechsler et al., 2004) to the lack of correlation between these measures within a sample of children and adolescents with FASD (Odishaw, 2007), it seems likely that prenatal alcohol exposure affects the relationship between IQ and adaptive behaviour. For this reason, it is important that policy makers recognize the special circumstance of persons with FASD, and allow for alternative measures to be used when determining eligibility for services for this particular population.

Based on the findings here, it could be argued that although the component scores derived from the CAS together offer the best predictors of parent-rated adaptive behaviour in children and adolescents with FASD, this still falls short of explaining the degree of adaptive deficits observed by caretakers. Using observational techniques and/or adaptive and behavioural measures by multiple informants may offer a more appropriate way to determine a need for service provision.

**Recommendations for Practice**

The following recommendations are based on the findings of this study in combination with findings from previous research studies in the area. A cognitive profile emerged on both the CAS and the WISC-IV and suggested strengths in the area of non-verbal reasoning, and weaknesses in the area of EF.

A focus on non-verbal, visual presentation of information appears to be the preferred way for many children and adolescents with FASD to process information. Capitalizing on strengths in the area of non-verbal reasoning to address weaknesses in the area of EF may be relevant in developing EF skills in persons with FASD. That is, using pictorial problem solving activities to develop EF skills in children with FASD may be useful.

Particular deficits were evident on the CAS Planning Component – an area that involves novel problem solving. There is some research to suggest the benefit of using verbalization, where poor problem solvers verbally describe how they are solving a problem, to identify errors in problem solving and to encourage development of problem solving abilities.

Particular weaknesses were also evident on the Working Memory Index of the WISC-IV. Research with children with FASD has shown the utility of teaching rehearsal strategies to improve working memory in this population (Loomes, Rasmussen, Pei, Manji, & Andrew, 2008).
**Recommendations for Future Research**

The current study, in highlighting the cognitive profiles of this group on two comprehensive intelligence tests, offers an important starting point for beginning to develop interventions that might target areas of weakness and capitalize on areas of strength. An exploration of the utility of cognitive interventions based on CAS cognitive profiles may offer some direction for meaningful intervention.

Given the limited sample size and the restrictions in EF measures employed in the current study, a future direction might involve a larger scale study to further investigate the nature of EF in children and adolescents with FASD.

A replication of the Miyake et al. (2000) design, where multiple lower order and higher order EF tasks are concurrently employed would begin to answer whether the EF tasks function similarly in a population with FASD as compared to a population without FASD. An exploration of verbal and non-verbal EF tasks within each target area would also further our understanding of the relevance of language and perceptual abilities to EF in persons with FASD.

The rationale of the current study was related to that of Schonfeld et al. (2006) who found functional assessments of EF to be predictive of social skills in children and adolescents with FASD. Extending the findings of the present study and that of Schonfeld et al. (2006), it seems relevant to concurrently explore the comparative predictive validity of a wide range of cognitive measures of EF with a more functional assessment of the same (e.g., BRIEF). Findings may help to identify particular tools that may be relevant in identifying persons in need of services. Combining this quantitative data with qualitative reports of family members and teachers may help to explicate the nature of the relation between cognition and adaptive behaviour in children and adolescents with FASD.
Appendix #1

Alberta Centre for Child, Family and Community Research
Funding Themes and Sub Themes

Early Childhood Development
• Early childhood well-being
• Children with disabilities, including Autism, FASD and Cerebral Palsy
• School Readiness
• Identifying the unique needs of young children in rural and urban First Nations and Metis communities

Middle Childhood and Youth Well Being
• Resiliency
• Youth at Risk
• Transitions
• Prevention of Suicide
• Support for Youth with Disabilities
• Mental Health and Concurrent Disorders

Family Capacity Building
• Family well being
• Family support systems
• Parenting skills and knowledge
• Parent-infant bonding
• Preparing for physical, social, emotional, cognitive and developmental transitions
• Mental well being

Community Capacity Building
• Building community well-being
• Rural Alberta communities
• First Nations, Metis and urban Aboriginal communities
• Culturally diverse or unique communities
• Partnering with unique-needs’ communities to develop new approaches to research
• Family violence and bullying
• Nurturing environments for children in care

Tracking Long-Term Outcomes
• Developing capacity to track long-term outcomes of government, community and private programs through existing data
• Developing new data to track long-term outcomes for Alberta’s children including family supports for children with disabilities
Appendix #2

Alberta Centre for Child, Family and Community Research

Grant Categories

**Topic-Directed Research Grants** are accepted only in response to a Request for Proposals (RFP) from The Centre. Successful proposals for the Topic-Directed Research Grants can be awarded up to $100,000 over a two year period. Previous Topic-Directed calls include FASD prevention and maternal mental well-being. Please check The Centre’s website for current RFPs - they are issued at least twice annually, and are designed to answer questions of special interest to policy makers. To receive RFPs directly, please email grants@research4children.com to be added to our electronic mailing list.

**Investigator-Driven Grants** are designed to fund research that relates to areas of research interest to The Centre. Investigator-Driven Grants can be awarded for an amount up to $100,000 over a two year period and require the submission of an LOI before a full proposal may be invited. Past grant recipients submitted proposals on topics like practice standards for children in care and the effects of educational intervention on fathers’ interaction skills with infants.

**Investigator-Driven Small Grants** are designed to fund research that relates to areas of research interest to The Centre. Investigator-Driven Small Grants can be awarded for an amount up to $40,000 over one year and do not require an LOI. Previous grants have funded small-scale research studies, an independent component or phase of a larger study, and community-based research.

**SEED Grants** are designed to support the planning and conceptualization of a research project. Up to $10,000 over a year can be awarded to successful applicants. Previously, these funds have been allocated towards team building, pilot projects, and feasibility studies.

**Knowledge Transfer Grants** are $5,000, one year awards intended to support activities that move research evidence into the hands of non-academics to inform policy and practice decisions and ultimately improve the well-being of children, families and communities. Previous projects include distribution of information about study outcomes to community stakeholders, preparation of educational resources, and the development of policy briefs and materials for service providers.

**Community-Driven Research Grants** are designed to support the development of a research project that assists a community organization in answering a research question of relevance to them. Previous collaborations have included organizations supporting in-school mentoring and therapeutic respite programs. The Centre recognizes the importance of high quality research in which communities are actively engaged, and where a range of methods and knowledge mobilization mechanisms are used. Researchers or Organizations interested in collaborating in this area are invited to contact The Centre to discuss potential partnership opportunities. There is no maximum value when matched with funds from the community and other partners; otherwise, the maximum is $150,000 over a two year period.

**Doctoral Awards** are designed to build Alberta’s research capacity in areas of research interest to The Centre, and are only available to post-candidacy Doctoral students. Each award includes funds of up to $50,000 over two years. Funds may be allocated towards research activities and student stipends.
Examples of past Doctoral projects include a study on efficacy of an Intervention for School Aged Children with Autism Spectrum Disorder and on risk and protective factors for addictive behaviours among urban Aboriginal Canadians.

**Post–Doctoral Awards** enable highly qualified doctoral graduates who are undertaking original research to prepare for careers as independent investigators in areas of interest to The Centre. Each award includes funds of up to $100,000 over two years. Funds may be allocated towards research activities and stipend. One Post-Doctoral project that received funding examined the lifecourse approaches of child health.

**The Westbury Legacy Award** will recognize community organizations and individuals in Alberta who have demonstrated exceptional commitment to the academic and/or professional growth of individuals (i.e. students/trainees/volunteers) working in the areas of child, family and community research with a $25,000 research allowance. The Westbury Award 2010 recognized Jeff Bisanz for his outstanding mentorship and contributions to the area of child, family and community research.
Appendix #3

Fetal Alcohol Spectrum Disorder (FASD)

What is FASD?

• FASD encompasses a broad spectrum of preventable birth defects and developmental disabilities that results from prenatal alcohol exposure (1-4).
• FASD includes fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), partial fetal alcohol syndrome (pFAS), other alcohol-related neurodevelopmental disorders (ARND), and alcohol-related birth defects (ARBD) (1, 2, 5-7).

Characteristics of FASD

• FASD-affected individuals may express any combination of physical, behavioural, cognitive, or psychosocial deficits, including severe growth restriction, intellectual and learning disabilities, difficulties focusing and sustaining attention, and poor judgement (8-10).
• Individuals with FASD are more likely to experience disrupted academic or job performance, difficulties with social interaction, trouble with the law, or substance abuse (1, 11-14). These disabilities affect individuals with FASD throughout their lives.
• How much alcohol was consumed, how often, and when, as well as “poverty, genetics, maternal stress, poor nutrition, and other prenatal exposures” can influence the severity of the disabilities on the child (15).

Key Facts on FASD

Across Canada and the world, there are conflicting messages communicated to society about prenatal alcohol exposure, which handicaps these people from making healthy decisions before, during, and after pregnancy (27, 28).
• According to the World Health Organization’s official statement on FASD, “alcohol consumption during pregnancy is related to various risks to the fetus, which includes Fetal Alcohol Spectrum Disorders. Alcohol consumption during pregnancy can also lead to spontaneous abortion, low birth weight and prematurity, and intra-uterine growth retardation” (29).
• Individuals with FASD often suffer from secondary disabilities, including mental health problems, incarceration and retention in the justice system, confinement, inappropriate sexual behaviors, alcohol and drug abuse, and school incompletion, all of which may reduce the likelihood of meaningful employment (30, 11).
• Incidence and prevalence of FASD varies from one geographic area to another and from one subpopulation to another; therefore, one cannot widely generalize from a study on one geographic area to another or from a study of one subpopulation to another (31, 32).
• Current evidence suggests that heavy drinking creates the greatest risk for FASD, however, the development of FASD is a complex interaction between maternal alcohol consumption patterns, fetal susceptibility, and maternal characteristics, such as age, nutrition, genetics, biology, and lifestyle (33, 34).
• Establishing rates of FAS/FASD and tracking these rates over time is important to determine where the need for resources is and to ensure appropriate allocation of resources (34).
• A comprehensive multidisciplinary diagnostic evaluation is the best diagnosis practice standard for FASD (35).
Prevalence Rates

- The consensus around FASD is that it is one of the largest forms of developmental delays and an entirely preventable tragedy (16).
- Although true prevalence rates are difficult to estimate, given that no clear diagnosis of FASD exists (17, 18), Canadian estimates of FASD are nine babies per every 1000 live births (19).
- There is Canadian data indicating greater prevalence in rural communities, foster care systems, juvenile justice systems, and Aboriginal populations (20).
- In Alberta, an estimated 23,000 individuals are living with FASD (21). This number is increasing as 300–400 babies are born each year with FASD (22).
- According to the Canadian Community Health Survey (2003), 13.9% of women reported drinking alcohol at some point while they were pregnant (22).
- A report by The Centre with data from the Aboriginal Children’s Survey 2006 revealed that 1.3% of Aboriginal children living off reserve in Alberta were diagnosed with FASD, which was significantly higher than the Canadian rate of 0.7% (23).

Relevance

- Given the estimated prevalence rates in Canada, there has been considerable concern over the costs of FASD to society (17, 18).
- The lifetime cost of supporting an individual born with FASD is approximately $1.5 million in Alberta (22), and between $1-3 million in Canada (24).
- In Alberta, the annual economic cost of FASD is an estimated $130 to $400 million (15).
- These costs result from increased health care needs, special education, social and vocational services, losses of productivity, and associated costs of secondary disabilities such as substance abuse, mental health problems, and unemployment and legal issues (3).
- For families with a child diagnosed with FASD, a recent Canadian study showed their annual costs for medical and other treatments was approximately $24,000 per year (20).
- Individuals with FASD between 0 and 21 years of age represent a potential annual cost of over $571 million based on the current Canadian population (20).
- Preventing just one percent of all newly diagnosed cases each year, for ten years, would save approximately $7.8 billion (25).
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