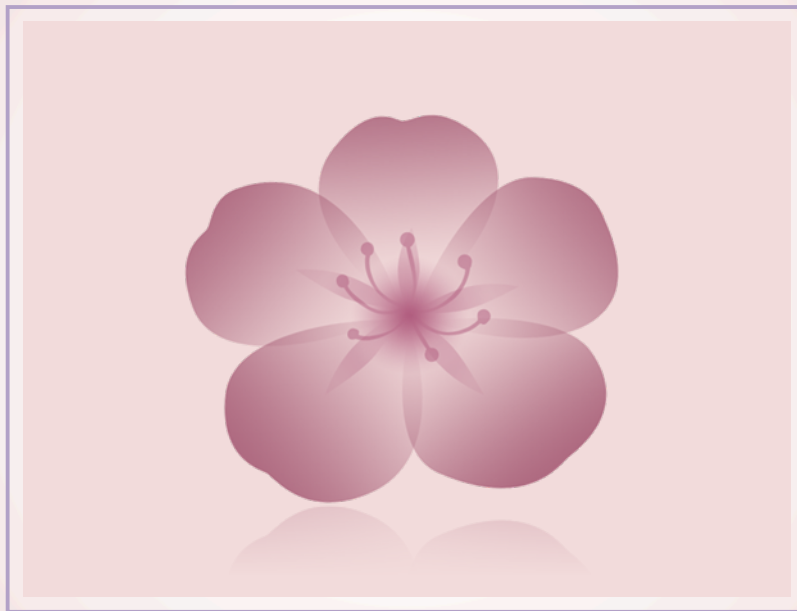


FASD LITERATURE REVIEW



[A SCAN OF THE LITERATURE, FASD BEST PRACTICE MODELS
AND SERVICE STANDARDS]



MARLYN BENNETT
2009

[THE VIEWS EXPRESSED IN THIS REPORT ARE THOSE OF THE AUTHOR AND DO NOT NECESSARILY
REPRESENT THE VIEWS OF THE STANDING COMMITTEE ON CHANGES FOR CHILDREN.]

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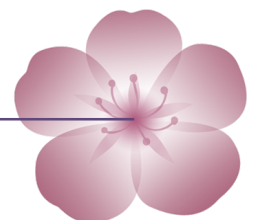
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Section 1 – Introduction and Scope of Review

The present literature review was commissioned by the FASD Best Practices Models and Standards Design and Workplan Development Team. The work of this team is part of seven sub-projects identified by the Intersectoral Partnerships Project.

This review synthesizes literature on current FASD research, best practices literature, existing FASD initiatives, and knowledge gained through experiences both within Manitoba and/or in other child welfare jurisdictions. The literature review is intended to inform and assist in the FASD best practice model(s) and service standards development process. The scope of this review centers on the following key areas:

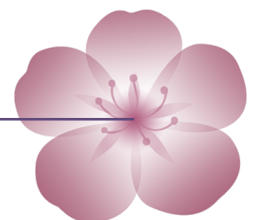
- Children affected by FASD who are involved with the child and family service system;
- Families and/or caregivers of children affected by FASD;
- Pregnant women at high risk of misusing substances and who are involved with the child and family service system; and
- Youth with FASD transitioning out of the child and family service system, including those who are or maybe involved in the justice system.

In some cases there is no existing literature or there is an absence of research available on the topic areas identified within the scope of this review. For instance, very little few resources exist which focus on service standards specific to working with and/or FASD populations. As with this particular example, recommendations for further research have been highlighted in a separate section of the review.

Literature Sources

This literature review is based primarily on academic writings found in peer reviewed and professional journals, federal and provincial government documents, and books and internet sources if found to be credible. Search methods included use of the Online Databases of Academic Search Elite, Humanities and Social Sciences Index, and PsychINFO. Bibliographies of relevant literature also proved to be valuable sources. The sources reviewed for this document were chosen on the basis of their relevance to the above topics, applicability of findings to the Canadian context, and the date of publication. The review was restricted to existing research and reports developed over the past 15 years (1993-2008), though in some cases older documents were included to further explore ideas presented in the literature¹. Numerous and extensive literature

¹ A list of annotated resources was previously compiled in February 2008. This review is based upon 109 References, 193 Authors, 94 keywords, 29 Periodicals and spans 15 publication years between 1993 and 2008. A subsequent re-review of these resources at the end of 2008 reveals that many of the resources in that previously compiled annotated list are inapplicable to the five areas outlined above but nevertheless do yield some relevant data. For the most part this paper focuses on material that speaks to the Canadian context.



reviews have already been conducted on FASD (Tait, 2000; Basford, Thorpe, William & Cardwell, 2004; Public Health Agency of Canada, 2005; Goh & Rosenbaum, 2005; Badry, Pelech & Norman, 2005; Guilfoyle, 2006; Hornick, Paetsch, Bertrand & Jacobs, 2008). This document therefore focuses on a broad overview of the existing literature but it is not intended to be an in-depth review on any of the individual areas identified above.

Background and Definitions

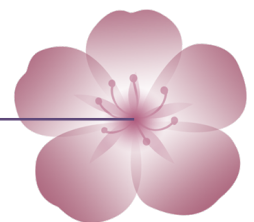
Fetal Alcohol Spectrum Disorder (FASD) is a permanent birth defect caused by maternal consumption of alcohol during pregnancy. The impairments exhibited by children can vary from subtle or mild to moderate or severe. It is a continuum ranging from mild intellectual and behavioural issues to the extreme often leading to profound disabilities or premature death. There is not one syndrome but a spectrum of disorders that represents a mix and match of FAS diagnostic components. Wachtel and Annis (2007) note that the terminology around FASD is ever evolving. Fetal Alcohol Spectrum Disorder (FASD is the umbrella term not a diagnostic term) for the range of effects that can occur in an individual whose mother drank alcohol while pregnant. The word “spectrum” in FASD acknowledges that Fetal Alcohol Syndrome is a continuum, with differing degrees of expression of dysfunction and malformation (Fast & Conry, 2004). Over the years at least five categories have been developed for diagnostic purposes and include the following:

Category 1 – Fetal Alcohol Syndrome (FAS) with confirmed maternal alcohol exposure characterized by a triad of signs:

- Prenatal and/or postnatal growth restriction (height and weight at or below the 10th percentile);
- Characteristic facial anomalies including short palpebral fissures, flat philtrum, and thin vermillion border of the upper lip;
- Central nervous system dysfunction. The central nervous system is composed of the brain and spinal cord. Damage to this area may be demonstrated by intellectual impairment and/or structural abnormalities, microcephaly, developmental delay, and a complex pattern of behaviours including extreme hyperactivity, aggressiveness, and poor judgment.

Category 2 – Fetal Alcohol Syndrome FAS without confirmed maternal alcohol exposure.

Category 3 – Partial FAS or FAE with confirmed maternal alcohol exposure: These terms are used to reflect points along the continuum of defects and impairments that are less evident than full-blown FAS. Children with partial FAS (or pFAS) exhibit some clear facial anomalies but children with FAE do not. Partial FAS is not necessarily a milder form of FAS because the signs, although they may appear to be fewer in number, may actually be just as debilitating as full-blown FAS. FAE (largely replaced by the pFAS and ARND) has been termed “the invisible disability,” because affected individuals, though seemingly normal, may suffer central nervous system disabilities rendering them at risk for severe behavioural and cognitive problems (Mitten, 2004). Most have no physical characteristics of FAS therefore we see no outward physical signs of the disability.



Category 4 – Alcohol-Related Birth Defects (ARBD): refers to individuals showing a range of physical defects in the skeletal and major organ systems or abnormalities of the heart, eyes, ears, kidneys, joint and limb anomalies and a history of maternal alcohol consumption.

Category 5 – Alcohol-Related Neurodevelopmental Disorder (ARND): Patients in this category will have evidence of central nervous system neurodevelopmental abnormalities and/or complex patterns of behavioural or cognitive abnormalities. Children, adolescents and adults with ARND may not demonstrate any of the facial features associated with the full syndrome (Slade, 2004).

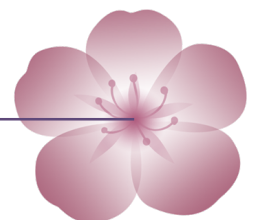
There are three specific criteria used in diagnosing individuals with FASD (Sokol & Clarren, 1989; Streissguth, Barr, Kogan & Brookstein, 1996). These are:

- Characteristic facial features;
- Reduced growth; and
- Central nervous system damage.

Differences in diagnostic categories are not based on severity of effect, but the presence or absence of confirmed history of prenatal exposure including one or more of the criteria mentioned above (Brown & Bednar, 2004; Coles, 2003). People with FASD are usually smaller, their faces may or may not look different and they have congenital brain damage. However, it is the brain damage that is the most significant as the brain damage is what brings affected individuals to the attention of the child welfare system or the criminal legal system, and has potentially devastating impacts on the day to day living of affected individuals (Rutman, La Berge & Wheway, 2005). And unlike other forms of disabilities, people usually can't see it. It is the invisibility of FASD that contributes to many of the challenges and social and systematic barriers that FASD affected people experience in everyday life (Rutman, La Berge & Wheway, 2005).

People with FASD are also often given a wide variety of diagnosis (O'Malley & Nanson, 2002). Mitten (2004) notes that co-morbidities can accompany FASD and can include attention deficit hyperactivity disorder (ADHD), attention deficit disorder (ADD), oppositional defiant disorder (ODD), attachment disorder, conduct disorder, personality disorder, and depression and suicide. FASD conditions may be misdiagnosed as one of these co-morbidities, especially ADHD among the middle class (Philp, 2003).

People of all ages may be affected. FASD is an equal opportunity disability (Philp, 2003). FASD is not hereditary and it cannot be cured. People affected by FASD will never recover from it and will live with it for their entire life. Individuals with FASD may look and seem normal; as a result this condition is often not diagnosed. FASD is a brain injury which may affect approximately 1% of people living in Canada (Robinson, Conry & Conry, 1987; Asante & Nelms-Matzke, 1985; Square, 1997; Williams, Odaibo & McGee, 1999; Habbick, Nanson, Snyder, Casey & Schulman, 1997). This means that there may be about 300,000 living in Canada today with FASD (Public Health Agency of Canada, 2005). FASD has been recognized in most countries of the world. The world incidence of FASD is unknown but estimates indicate there are 1.9 cases of FASD per 1000 live births (Tait, 2002). Health Canada states that there may be incidences of 1 to 3 cases of FASD per 1000 births (Health Canada, 1996). The clinical literature suggests that where a child has been diagnosed with an alcohol related birth defect, the chances an



older sibling has been similarly affected is about 170 per 1000 live births while the risk of a *younger* sibling being similarly affected is about 770 per 1000 live births (Berg, Kinsey, Litke & Wheway, 1995). It has been recognized that FASD is under-diagnosed. This indicates a lack of awareness and knowledge as well as bias, prejudice, and discomfort in the medical, educational, mental health, social sciences as well as in the legal, justice and correctional fields (Chavkin & Britbart, 1997).

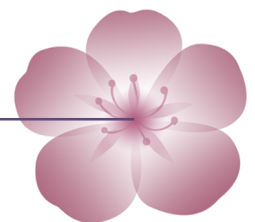
Individuals with FASD face a number of deficits in relation to cognitive processing and experience a range of social and emotional challenges. The deficits in cognitive processing can include:

- Poor short term / working memory and “flow-through” memory (for example, individuals might appear to know sometime or how to do something but then forget about it the next day);
- Difficulties with communication, particularly receptive language (i.e. they talk well but understand little) and speech disorders;
- Confabulation (for example, information may be made up to fill in gaps in memory or understanding, and/or in an effort to please others); this is often perceived as lying;
- Learning difficulties and information processing problems;
- Difficulties with attention and concentration;
- Difficulties with generalizing information, forming linkages, and abstract reasoning;
- Difficulties with perseveration (having difficulty “switching gears” when doing a task, or doing the same activity or thinking/saying the same thing repeatedly);
- Difficulties with math, and in managing time and money;
- Difficulties with motor skills and balance;
- Poor judgment and problem solving abilities;
- Difficulties in relating behaviours to consequences;
- Difficulties with executive functioning (for example, being able to plan and organize) (adapted from Rutman, La Berge & Wheway, 2005).

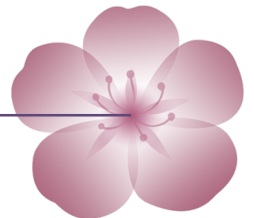
Social and emotional challenges include:

- Difficulties in regulating emotions (i.e. going from being calm to being agitated, as a result of becoming overwhelmed);
- Difficulties in reading social cues and in understanding and expressing emotions;
- Lack of social boundaries or sense of “personal space.”
- Difficulty showing remorse; and
- Difficulties in controlling anger (Rutman, La Berge & Wheway, 2005).

Fetal Alcohol Spectrum Disorders preventable. The sole cause of FASD is prenatal exposure to alcohol. A FASD diagnosis is not a developmental delay. Children will never recover or “catch up” (Tindle, 2002). And while affected children will never recover from FASD, the literature indicates that if diagnosed early coupled with intervention, the outcomes for FASD affected children can be positive (Streissguth & Kanter, 1997). Early diagnoses can help make the most of the brain’s early development and give parents and caregivers the tools they need to help their child avoid secondary disabilities that might develop later in life. To be diagnosed, children must meet criteria that involve a behavioural and learning checklist and a physical exam. Confirmation that the birth mother drank while she was pregnant is also needed. However, this is particularly difficult to get as birth mothers often feel blame is



being pointed at them, and, as a result, may withhold this important information (Tait, 2002). Accurate diagnosis is best before children turn 2 years old. Diagnosis at adolescence and into adulthood gets more difficult and may not be possible unless conducted by a skilled clinician experienced in adult and youth diagnosis (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004). An extensive literature review on the various screening tools and methods developed particularly for children and youth with fetal alcohol spectrum disorders was completed by Goh and Rosenbaum for the Canadian Association of Paediatric Health Centres in 2005. In the meantime, medical assessments in Canada remain difficult to obtain and Tait (2001) notes that in some cases they are almost virtually impossible to get.



Section 2 – Children Affected by FASD and Involvement with Child and Family Service Systems

Overview:

- Very few Canadian resources exist focusing specifically on the correlation between children with FASD and child welfare involvement;
- The leading resource remains that conducted by Don Fuchs, Linda Burnside, Shelagha Marchenski and Andria Mudry. This was a quantitative study published through the Centre of Excellence for Child Welfare. Their look at children with FASD involved from a larger project that looks specifically at children with disabilities that are involved with child welfare system within Manitoba;
- Another Manitoba specific project was conducted in Manitoba by Alex Wright, Diane Hiebert-Murphy, and Gwen Gosek. Their qualitative study, published through the First Nations

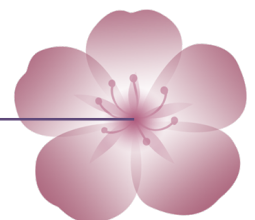
Child & Family Caring Society of Canada, did not specifically focus on children with FASD and their involvement with child welfare, it does nevertheless exposed First Nations child welfare agencies' concerns for issues pertaining to FASD (i.e. the primary focus of this study was understanding the needs of Aboriginal children in care with learning and behavioural disabilities and how Aboriginal agencies are dealing with the special needs of children who may be FASD);

Sample of search terms used:

- Child in care with fetal alcohol spectrum disorder
- Child in care with FASD
- Children in care with FAS/FAE, FASD
- The child welfare system and children with FASD
- Child welfare involvement with FASD affected children and families
- Child and family services and children with FAS/FAE, FASD
- Child welfare services to children with FASD
- Servicing children in care with FASD
- Children with FASD and child welfare
- Children with FASD and foster care involvement
- Children with FASD and out-of-home placement
- Standards of care, FASD
- FASD standards
- FASD practice standards
- Practice standards and fetal alcohol spectrum disorder
- FASD, standards
- Practice standards with children in care with FASD

Very few Canadian resources exist that focus directly on this specific topic. In research conducted in the United States by Streissguth and colleagues (2004), environmental circumstances frequently found in association with prenatal alcohol damage are early maternal death, living with an alcoholic parent, child abuse and neglect, being removed from the home by authorities, experiencing repetitive periods of foster care and other transient home placements, and being raised by adoptive or foster families. In addition, the families that raise children affected by FASD are highly variable. They may have no knowledge of the prenatal exposure history which makes it difficult to obtain accurate diagnoses of possible alcohol-related problems. Or, they may be the birth families themselves, with a mother who may or may not be in recovery. To date these environmental characteristics have not been quantified and examined in light of their contribution to adverse psychosocial outcomes for the child with FAS or FAE.

The leading Canadian source on children with FASD involved with the child welfare system is from a ground breaking Manitoba study published through the Centre of Excellence for Child Welfare by



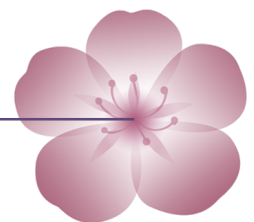
colleagues Fuchs, Burnside, Marchenski and Mudry in 2007. The focus on children with FASD involved with child welfare evolved from a larger study that looked at the incidence of disabilities among children involved with the Manitoba child welfare system.

In their study of children in care with disabilities in child and family services agencies in Manitoba, Fuchs et al. (2005) found that 11.3% of the total number of children in care at September 1, 2004 were diagnosed with FASD. Further, a considerable number of children were suspected of having the condition, as they were in the process of being tested for FASD or were receiving services consistent with a diagnosis. In addition it found that 17% of all children in care were affected by the condition. An overwhelming majority (89%) of children with FASD was in permanent care of an agency and had limited contact with biological parents. Consequently, child welfare agencies in Manitoba have significant responsibility for these children until their age of majority, requiring agency staff and caregivers to be cognizant of the special needs of this population during childhood and adolescence through to the transition to adulthood.

In particular Fuchs, et al., (2005) found that of the children in care with FASD, 94% are of Aboriginal descent. The study found that the majority, 81% respectively were First Nations (status or Treaty Indian), while 9% were Métis and 4% were non-status Aboriginal. The rate of disabilities for Aboriginal people has been reported to be twice as high as that of the non-Aboriginal population in Canada, and the rate of FASD in some Aboriginal communities may be significantly higher as well. It is possible that First Nations families who live on reserves may be disadvantaged in receiving services for their children with disabilities, since reserves fall under federal jurisdiction and social services are typically provided by provinces and territories. For these reasons, there may be an increased risk of Aboriginal children with disabilities coming into care. Gosek, Wright and Hiebert-Murphy (2005) published results on a two year project that focused on understanding the needs of Aboriginal children and youth with learning and behavioural disabilities in the care of twenty-nine First Nations child welfare agencies across Canada. Focusing on the learning and behavioural disabilities of First Nations children and youth was considered too narrow and in many cases the term (learning and behavioural disabilities versus FASD) was unfamiliar to most of the FNCFS Agency participants. The discussion was expanded to include a variety of specific behavioural concerns and disabilities primarily known by service providers in the First Nations field as being FASD related.

In addition, Fuchs et.al (2007 & 2008) found that children with FASD are coming into care of child and family service agencies at younger ages any other children; they are staying in care longer and spending more of their childhood in care than any other group of children. In addition, children with FASD in care costs are greater than other children in care (Fuchs, Burnside, Marchenski, Mudry & De Riviere, 2008). This has major implications for the need develop appropriate care services while these children are in care and a significant need for services and resources as youth FASD transition out of Care.

In Manitoba, it has been shown that one third of children in care fall within a broad definition of disability and 17% of children in care within the Province's child welfare system are affected by diagnosed or suspected Fetal Alcohol Spectrum Disorder (Fuchs, Burnside, Marchenski, & Mudry, 2005). FASD encompasses a range of conditions that are caused by maternal alcohol consumption during pregnancy. Indicators include physical characteristics and inhibited growth, neurodevelopmental problems, and behavioral and cognitive difficulties that are inconsistent with developmental level. As a

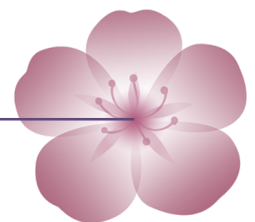


result, children with a diagnosis of FASD present agencies with an array of complex and variable needs. Both the significant proportion of children with FASD in care and the nature of their needs make it important to understand the relationship of this population to child welfare agencies. The purpose of this research was to gather information on the legal status and placement histories of children with FASD in care and compare those histories to the histories of children with other disabilities and children with no disabilities. The data clearly showed that children with FASD had come into care at a mean age that was at least a year younger than any other group of children. They became permanent wards more quickly. Their mean age at becoming permanent wards was two years younger than children with no disabilities and three years younger than children with other disabilities. Placements followed a similar pattern. Legal status and placement histories confirmed that children with FASD spend a greater proportion of their lives in care of an agency than other children. Although Voluntary Placement Agreements were frequently used for other groups of children, they were seldom used for children with FASD. The number of children with FASD and their demonstrated dependence on child welfare agencies emphasizes the importance of strategically addressing their needs.

Further, information from the Addictions Foundation of Manitoba that 1200 women of childbearing age were screened for addictions programs in the 2005-2006 year gives clear indication that there is an ongoing risk of increasing demand for services for children with FASD. The implications for agencies include increasing demands on the expertise of workers, caregivers and service providers and the program supports currently available; and increasing need for comprehensive service plans to support the transition of children with FASD into adulthood. Manitoba social policy must address the need for: capacity building, greater accessibility to diagnostic services and culturally relevant prenatal alcohol use prevention programs. Further research is needed to identify the unique developmental needs of children with FASD who are in care (Gough and Fuchs, 2006). More and more children are being born with fetal alcohol spectrum disorder and governments must increase support for the ones who are ending up in foster care, say Fuchs and his colleagues from the University of Manitoba. On the other hand, others have indicated that as better information about FASD and the limitations faced by individuals becomes readily available and becomes more widely disseminated, the unacceptable high rate of maltreatment by this population may decrease (Clarke, Lutke, Minnes & Ouellette-Kuntz, 2004).

Need for more Training and Education about FASD

Understanding the knowledge, attitudes, and beliefs about FASD by professionals working in the child welfare field are critical to understanding and obtaining the services needed by children and families affected by FASD. No Canadian sources appear to capture the essence of the various child welfare systems' knowledge and attitudes about the FASD affected children and families they service within their jurisdictions. Very few child welfare workers understand the epidemiology or how to recognize children with FASD or know of methods for working with children and families impacted by FASD. American research (recently published in a Canadian journal) indicates that human service professionals (e.g. those working in the fields of child welfare, child protective services, foster care, and health care), critical to prevention of primary and secondary disabilities among children and youth who are or could be affected by prenatal exposure to alcohol, are basically knowledgeable about primary prevention but lack additional education and assertive protocols to help them in their work with families and children already affected by FASD (Caley, Syms, Robinson, Cederbaum, Henry & Shipkey, 2008). A similar study and finding was conducted in Canada among health professionals (Public Health Agency of Canada,



2005) where it was found that while Canadian health care professionals are aware of some aspects of FASD, there is still a need for more education and training to support these individuals in their work of caring for both individuals at risk for having a child with FASD, and for those with FASD and their families. Similar findings about knowledge and awareness of FASD have been replicated among Canadian Physicians (Nanson, Boleria, Snyder, Morse, & Weiner, 1995), Psychiatrists (Tough, Clarke & Hicks, 2003), nurses (Caley, 2006) criminal justice professionals (Cox, Clairmont & Cox, 2008), including the educational system (Manitoba Education, Training and Youth, 2001; Alberta, 2004; Healthy Child Manitoba, 2007).

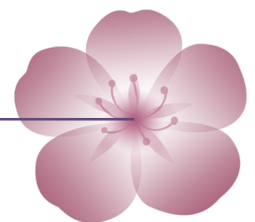
Public education, awareness and knowledge about FASD remain among the goals important to the governments of Canada in the fight to prevent FASD, identifying those affected and referring them for appropriate diagnosis and services. Training, education and knowledge about best practices to working with FASD affected families has been identified by service providers within the child welfare field as particularly important. Much of the available literature on FASD is medically generated. Very little research has been generated from the child welfare and social services standpoint. It is however generally agreed that additional training in all of the following areas is needed in all disciplines:

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

The First Nations Child & Family Caring Society of Canada and Paukuutit Inuit Women of Canada jointly mapped the types of FASD services and training opportunities available to First Nations and Inuit service providers and community members across Canada (Irvine & Vincent, 2006). Their findings recognize that there is a need for adequate and on-going FASD funding, a full spectrum of on-going and comprehensive FASD training, including the need for a full spectrum of FASD services, specialized programs and sustainable FASD diagnostic infrastructure for First Nations and Inuit service organizations. The need for developing sustainable partnerships and networks of collaboration were also recognized as important to the FASD needs of First Nations and Inuit communities. The need for FASD targeted services and FASD training needs of First Nations and Inuit communities and agencies is particularly great and vastly underfunded if First Nations and Inuit organizations if they wish provide similar services in comparison to mainstream social work agencies.

Standards of Care for FASD Affected Children in Care

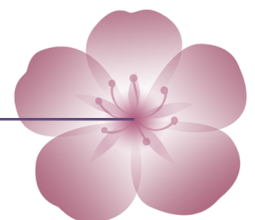
Standards of care for children involved with the child welfare system have been developed in all provinces within Canada. As with legislation and policies, standards of care for children and families involved with child welfare systems vary between provinces, territories, and First Nations agencies (Farris-Manning & Zandstra, 2003). Standards of care for children involved with child protection systems were developed to describe activities and services required during distinct phases of child protection



service. Generally speaking, practice standards guide social workers in how they provide services to children and families involved in the child welfare system throughout all of the phases of service. Until recently, no standards of care existed for children in care with FASD (Coles, 2003). Practice standards, particularly for children in care with FASD, have now been developed and implemented in at least two provinces in Canada: British Columbia and Alberta. Plans to develop standards in relation to children in care with FASD are also underway in other provinces such as Manitoba and Ontario (Manitoba, Child and Family Services Standing Committee, 2007; Ontario, Children and Youth Services, 2006).

The first province to develop practice standards with respect to children in care with FASD was the province of Alberta (see Southwest Alberta Child and Family Services, 2003, <http://www.southwestalbertacfsa.gov.ab.ca/whatsnew/pdf/FASDstandards.pdf>). It was identified as early as 2001 that children in care with FASD within the Province of Alberta were not being adequately served by existing standards of care within that province's child welfare system (Badry, 2009). This led to the design of practice standards specific to the needs of this population of children in 2002. Case management standards were drafted in the following areas: screening for FASD, child assessment, determining parenting ability, service plans, service plan reviews, home visits, case manager contact with children in care and foster parents, child and family awareness of FASD, permanency planning, transition planning to adulthood, FASD training for child welfare staff, and workload standards for caseworkers. Additionally, program standards were created in relation to kinship care, foster care, residential care, adoptive services/private guardianship and family preservation and youth mentoring services. Policy regarding the application of the standards was developed in early 2003. The pilot project ran from July, 2003 to December, 2004 (Badry, 2009). The standards developed by Alberta Children's Services have since been field-tested, fine tuned and evaluated by the Faculty of Social Work, University of Calgary. The intent of that evaluation was in capturing the experiences of caseworkers and foster parents who applied the standards and evaluating compliance with the standards (see final report by Badry, Pelech and Norman, 2005). Some of the key findings regarding the application of and compliance with the FASD practice standards as highlighted by Badry (2009) were:

- While the Pilot group experienced higher rates of placement change before and during implementation of the Practice Standards, there was a significant decrease in placement changes over time resulting in a convergence of mean placement changes over time.
- Consistent patterns of reduced risk behaviors and school absences were associated with the implementation of the Practice Standards
- Specific training in FASD supports caseworkers and foster parents in working with children and in meeting their needs more effectively. Training opportunities are valued and more specialized training is required.
- Caseworkers and foster parents were invested in the application of the standards, valued the experience, and the opportunity to reflect on their practice.
- Family visitation is a major site of conflict and tension, and considered to be the biggest factor in the "disruption" of the life of the child by foster families.



- The application of standards appeared to minimize other life disruptions such as school absences, behavioral difficulties, and change of placement.
- The diagnosis of FASD impacts the emotional well being of the child and leads to a key recommendation that a protocol for disclosure of FASD to children and families should be jointly established between diagnostic clinics and child welfare agencies.
- The use of respite should be negotiated with foster families.
- The standards state that there should be a minimum of two children with FASD in a home, and this is a source of conflict for some foster families.

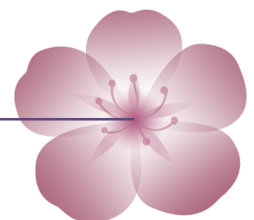
Since the development and subsequent evaluation of Alberta's Practice Standards, the Province of British Columbia has also moved to develop a 10 year plan and "Program Standards" in providing support to families of children and youth with Fetal Alcohol Spectrum Disorder and similar conditions (British Columbia, Children and Family Development, 2008). Under the Province of BC's plan, two new services (guided by program standards) are now available to assist families of children and youth with FASD and similar conditions:

- **Key Workers:** Key workers assist families in understanding FASD by providing education and information specific to the needs of the child and family. Key workers are familiar with community resources, assist families in accessing support, health and education services and are involved in the development of local support services. They also provide emotional and practical support to families. Key workers assist families to build on their strengths and recognize that children with FASD do best when their individual strengths are recognized and built upon in a supportive environment adapted to meet their needs. Key worker are expected to work with parents, family members, adoptive parents, caregivers and service providers in identifying ways to adapt the child's environment in response to the child's needs. The key worker also strives to empower the family to become their own best advocates for their child.
- **Parent Support:** Parent support includes local parent and grandparent FASD training, parent mentoring and parent support groups. Key workers can provide parents with more information on supports that may be available in or near their community.
- The Key Worker and Parent Support Program Standards can be found at http://www.mcf.gov.bc.ca/fasd/pdf/kw_guidelines_june_08.pdf.

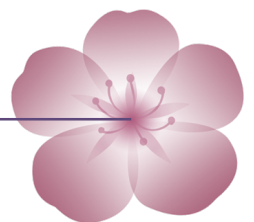
In addition to the need for practice standards for children in care with FASD, the available research has consistently identified the need for the development of standards across a number of FASD related areas²:

- *Pre-natal screening standards* (Tait, 2000; Basford, Thorpe, William & Cardwell, 2004; Guilfoyle, 2006)

² As these areas are not the focus of this review, I have merely identified some of the areas where the need for the development of standards has been alluded to. This is by no means an exhaustive list.



- *Assessment and diagnoses* (Public Health Agency of Canada, 2005; Goh & Rosenbaum, 2005).
- *Province wide training and education* (Public Health Agency of Canada, 2006; Irvine & Vincent, 2006)
- *Prevention* (BASFORD, Thorpe, William & Cardwell, 2004)
- *Intervention* (Malbin, 2005; Badry, Pelech & Norman, 2005)
- *Recognizing and diagnosing inmates with FASD in the correctional system* (Hornick, Paetsch, Bertrand & Jacobs, 2008).



Section 3 – Families and caregivers affected by FASD

Overview:

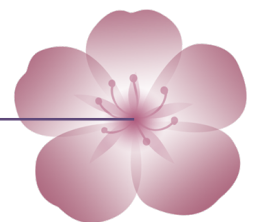
- Two specific studies conducted in Manitoba shed some light on the significant impact and toll that caring for children and adolescents with FASD can have on foster and adoptive parents – these are based on the doctoral and masters studies conducted by Kathy Jones and Holly Gammon specifically;
- Parents become advocates once children become older and realization that there are literally no services within the community that address or meet the needs of young people with FASD;
- A third set of prairie based studies highlights reasons why individuals would consider fostering children with FASD. This research focuses on instances that would cause placements of children in care with FASD to break down – conducted by a Professor previously with University of Manitoba but now at University of Western Ontario;
- Idea of a “second brain” referred to in the literature - Over 80% of people with FASD are unable to function well enough to maintain employment or live on their own in the absence of supports – much of that support comes from the families (mostly mothers) and who choose to raise children/youth affected by FASD and act as “second brains”;
- Very little information is known and available about the needs of the foster and adoptive parents who take on the task of raising children with FASD or what motivates these individuals to foster and/or adopt children with alcohol-related disabilities.
- Literature also addresses challenges faced by adults with FASD who become parents. Individuals with FASD also become parents but research on the challenges faced by adults with FASD who are parents is very limited and perhaps non-existent within the Canadian context.
- Visitations with birth family – literature does not address the role of the family of origin in the lives of children/youth affected by FASD – but seems to be an area that might be of importance given that the majority of children/youth with FASD live in foster care situations.
- Many resources have been developed offering help and guidance to families and caregivers parenting children affected by Fetal Alcohol Syndrome. A list of some of these sources are highlighted.

Sample of search terms used:

- Families and caregivers of children affected by FASD
- Families affected by FASD
- Needs of parents with children affected by FASD
- Parenting children with FASD
- Parenting Children Affected by Fetal Alcohol Syndrome
- Resources for parents with children affected by FASD
- Raising children with FASD
- Adopting and/or Fostering Children with Fetal Alcohol Syndrome Disorders
- Supporting parents with children affected by FASD
- Foster parents raising children with FASD
- Living with a child with Fetal Alcohol Syndrome
- Parents with FASD
- Parenting with FASD
- Alcohol-affected parents

The Challenges and Needs of Caregivers

Children who have FASD live with either their biological parents, with foster parents or they are adopted. Along with the rising incidence of FASD, it has been noted that children with FASD are among

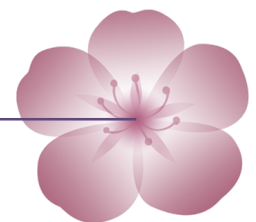


the fastest growing group of children entering the child welfare system (Stratton, Howe & Battaglia, 1996). Other research indicates children with alcohol-related diagnoses are overrepresented in the child welfare system (Aronson & Hagbert, 1998). Other circumstances frequently found in association with prenatal alcohol damage are early maternal death, living with an alcohol parent, child abuse and neglect, being removed from the home by authorities, experiencing repetitive periods of care and other transient home placements, and being raised by adoptive or foster families (Streissguth, Bookstein, Barr, Samson, O'Malley & Young, 2004). Those who remain with their birth mothers may experience stress if the mothers continue to drink (Coles, 2003). Removal from their biological homes and subsequent placement in foster and adoptive care is often the only way to ensure the needs of alcohol-affected children are met (Tindle, 2002). The majority of the sources consulted for this review however confirm that 80% of children with disabilities stemming from alcohol-related birth disabilities grow up in state care (Streissguth, Bookstein, Barr, Samson, O'Malley & Young, 2004; Brown & Bednar, 2004; Coles, 2003). Regardless of where children with FASD may live, there are challenges in promoting the continuity of care issues between living arrangements for children with FASD who come into care for only a short term, remain in care over a longer term or are permanently placed (Brown & Bednar, 2004; Fuchs, Burnside, Marchenski, Mudry & De Riviere, 2008). First Nations families, communities and service organizations are particularly disadvantaged in that they are often underfunded in providing FASD services (Blackstock, Loxley, Prakash & Wien, 2005; Irvine & Vincent, 2006).

The needs of individuals with FASD are great. A range of support programs and services to families and children with FASD will be required throughout their lifetimes (Coles, 2003). For some individuals the damage from FASD is minimal but for others the damage causes serious physical, behavioral and neurological impairment that is irreversible and has lifelong impacts. The impact of FASD on families raising alcohol-affected children and adolescents are complex and multi-faceted, not to mention exhausting. The stress of caring for children and youth with FASD complexities can take a toll on families (Marcellus, 2008). Four areas have been identified to have significant impact on families. These were identified by Gelo and O'Malley (2003) as:

- physical health of the child/adolescent
- mental health of the child/adolescent
- financial stress on the family
- emotional stresses of care giving on the family

Children with FASD often have co-occurring medical conditions resulting from their disability. These may be birth defects (from ARND), and can include kidney, liver, cardiac and feeding problems along with a range of other issues. These physical problems require medication but may also complicate the child's response to the medication. Aside from the effects of medication for other underlying conditions, children/adolescents with FASD are also known to have number co-morbid and complex mental health problems. It is not unusual to see features of ADHD with co-morbid anxiety or mood features in a child with FASD, as well as developmental delays in areas such as gross or fine motor, language, intellectual and social functioning. The use of medication in patients with FASD who have psychiatric disorders is further complicated by the response of an alcohol-damaged brain to psychotropic agents. The response to stimulants for ADHD, anti-depressants and/or mood stabilizers may be marginal if the underlying symptoms are more related to the core problems of brain damage in children/youth with FASD.



The constant balance of caring for children/adolescents with FASD and the need for resources is an ever present responsibility to those tasked with the management of these complicated children/adolescents. In addition, these children/adolescents impact many different systems throughout their life and each has long-term implications for the care of these individuals. It has been noted that the behaviour of children with a FASD could vary considerably from day to day and context to context (Timler & Olswang, 2001). The systems that will become involved in the life of children/adolescents with FASD include:

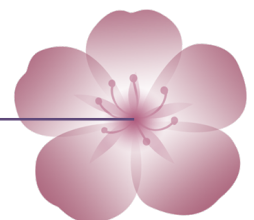
- Health care system
- Mental health system
- Education system
- Child welfare system
- Vocational/rehabilitation system
- Disability system
- Chemical dependency system
- Criminal justice system (Gelo & O'Malley, 2003, p.3).

The literature also indicates that there are markedly different financial burdens for those who adopt versus those who foster children/adolescents with FASD (Gelo & O'Malley, 2003). Families who adopt children, who have special needs related to FASD, often lose out on subsidies only available to children in foster care. A case in point was provided by Gelo and O'Malley (2003) where they stated that a foster mother living within the United States who is caring for a child with FASD was given the following subsidies:

Basic rate: \$296 / month
Special rate: \$141.50 / month
Exceptional: \$300 / month
Respite care: 16 hours / month
Day care: \$140 paid / month
Mileage: 31 cents / mile

The total amount of the above mothers' subsidy from the government was \$1270 per month. When this child was adopted, this amount fell to \$285 per month (representing a 77.6% decrease in funding). This decrease in funding, Gelo and O'Malley note, is a huge disincentive and a financial penalty to those who wish to adopt children with special needs or the children with FASD who they have become attached to. While the above example was drawn from an American source, it is evident that the extent of the financial burden to the child welfare system and for families, who care for children with FASD, is just as enormous within the Canadian context. There is a need for creative avenues to help fund both foster and adoptive families caring for FASD affected children/adolescents. Other research has noted that foster parents tend to be better resourced than adoptive parents, who in turn, are better resourced than biological families (FASD Community Circle, 2005). First Nations families are further disadvantaged by a lack of adequate funding and attention to this issue (Gosek, Wright and Hiebert-Murphy, 2005).

Family members need to be ever vigilant as children/adolescents with FASD are at a higher risk for physical and sexual abuse and/or assault (Dubenski, 1997; Kelly 2003; FASD Support Network of



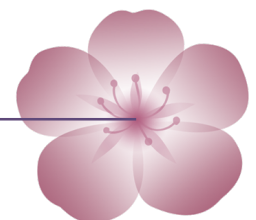
Saskatchewan, 2007). Impulsiveness, lack of inhibition, and naiveté is common among individuals with FASD, regardless of age or gender. Because of the lowered abstracting abilities and poor social skills exhibited by individuals with FASD, they are at a high risk for sexual exploitation (Rasmussen & Wyper, 2007). Some studies of children with FASD suggest that they are at an increased risk for maladaptive behaviour that may lead to criminal offences (Conry, 2000; Rasmussen & Wyper, 2007).

The emotional demands on the individuals in families who care for children/adolescents with FASD are also enormous. Emotional stress is one of the unspoken stresses of caring for these children. The demands of nurturing are constant and ever changing and parents can develop “compassion fatigue” which has been described in the literature as similar to the term “burnout.” Compassion fatigue is very real and is sometimes subtle. Symptoms of compassion fatigue can be as simple as a headache or backaches. Gradually over time, these systems can manifest in severe depression and in some cases has lead to marital discord. For foster families caring for infant and young children, the reality is that caregiving involves day and night hands-on involvement by everyone in the household. 24-7 care frequently results in fatigued parents and children, overscheduled families, restricted relational and recreational opportunities for core family members, and a lack of time and opportunity to develop and maintain external relationships (Marcellus, 2008).

Gelo and O'Malley (2003) also noted that compassion fatigue is also exacerbated when professionals fail to understand the complex needs of children/adolescents with FASD. The way the medical profession responds to parents who have children/adolescents with FASD often invalidates parent's desire to have the problems of the child understood. An extreme example is when parents are seen by the medical professionals as being over-responsive and seen as getting their needs met through the child or adolescent. Gelo and O'Malley (2003) indicated that mental health professionals have at times blamed parents for fabricating their children and/or adolescents' problems, even to the extent of suggesting parents are exhibiting classic signs of Munchausen's syndrome by proxy.

It is important that parents and professions be knowledgeable about the possible development of compassion fatigue among caregivers. Such sensitivity will help parents and professionals to develop strategies to keep caregivers from burning out and will help maintain the stability of the environment surrounding the child/adolescent with FASD. Gelo and O'Malley (2003) indicate that it is essential to understand and recognize the stress of care giving and its emotional risk to parents who have many roles. It is equally important that child welfare and health professionals support and validate these roles to nurture the parent/child bond. Caregivers need support groups, extra financial assistance and respite should be regularly planned and culturally appropriate (Tindle, 2002). Respite care is also important to ensure that families have time to nurture themselves. Caregivers also need the social support of extended family, friends and government agencies as well as help from professionals who understand the behavioural and educational manifestations of their children's disabilities (Tindle 2002). The importance of training parents to understand the multi-faceted issues of children with FASD is essential to care givers' emotional, mental and financial wellbeing.

The other area of emotional stress is in the realization that the child with FASD is less than “perfect” and that family members' may need to grieve for the loss of an “ideal family” and for what might have been. Many families experience denial, anger, and despair. Bargaining and acceptance have also seen in



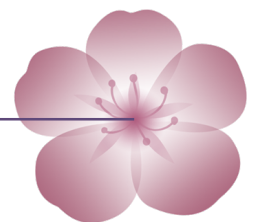
families who are dealing with the grief on different levels of the continuum upon learning that their child has been prenatally affected by alcohol (Gelo & O'Malley, 2003).

The importance of early identification of FASD is essential as children who are undiagnosed may be put in the care of unsuspecting families. Tindle (2002) notes that children who have been undiagnosed can potentially destroy families who have no idea what they are dealing with. Without such a diagnosis, it will be difficult for caregivers, teachers, child welfare and health care workers to provide suitable support and adequate intervention. The whole point of getting a diagnosis is so that an appropriate intervention plan is developed (DeVries & Waller, 2004). Unfortunately, FASD is often an invisible handicap because it is seldom identified at birth and it is rarely disfiguring. Most children look normal and their development on most fronts appears normal. It is usually when a child reaches the age of 6 years or enters the educational system when things begin to appear out of the ordinary. Problems with the child's behaviour are often blamed on inadequate or poor parenting (Tindle, 2002). Challenges experienced by these children are neurological as a result of brain damage and not necessarily emotional or environmental issues (although children/adolescents with FASD may experience secondary disabilities in adverse social and environmental circumstances – this is explained later). The symptoms experienced by children/adolescent with FASD are not as a result of being developmentally delayed. Children with FASD will never “catch up.” The underlying issues are not as a result of poor parenting but because of damage to the brain. Providing love will not “fix” the situation for the child but children can function better in stable environments when they have constant structure and guidance and access to resources to ensure their multi-faceted needs are met (Jones, 2004).

Two specific studies (Jones, 2004; Gammon, 2002) conducted in Manitoba shed some light on the significant impact and toll that caring for children and adolescents with FASD can have on foster and adoptive parents specifically as it is experienced by those looking after First Nations children and youth living with FASD. The first study was conducted by Kathy Jones was part of her requirements for completing a doctoral degree (Jones, 1999) while the second study, conducted by Holly Gammon for her Master of Social work degree (Gammon 2000), examined the lived experience of foster and/or adoptive mothers' caring for adolescents and young adults affected by prenatal exposure to alcohol. These specific studies are discussed briefly in the paragraphs below.

Jones (1999, 2004)

Jones (2004) explored the experiences of long-term foster parents raising children with FASD in her doctoral dissertation (1999). She paid particular attention to some of the specific problems facing parents of adolescents. All of eight of the foster parents in her study had fostered their children between seven and seventeen years. All were fostering for the same First Nations child welfare agency and were fostering between them a total of fourteen First Nations children ranging in age from 4 to 18 years of age. Ten of the children were under twelve years of age while the remaining four children were adolescents. Jones indicates that the majority of the children (11 of 14) had been placed in their current foster home before their first birthday. They had physical and emotional needs that ranged anywhere from “quiet, shy children to children with a high level of physical aggression towards others” and “that all of the children required intense support from their parents in order to be able to manage on a day-to-day basis” (Jones, 2004, p.3).

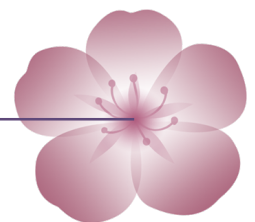


Jones' findings indicate that while these children had "endless needs." All the foster parents had developed a protective bond and were able to normalize some of their children's problems and needs. Challenges faced by some of these children as identified by the parents included an inability to demonstrate an emotional bond with the family, hyperactivity and aggression, as well as issues related to the physical needs and demands of the child. Jones notes that while home life created some stresses for foster parents, parents recognized these problems were overshadowed by the problems foster parents and their children faced once outside community-based resources are accessed as their children grow older. Many times these problems resulted when community systems did not support, or were not sensitive to the needs of their foster children. In particular families reported that as children with FASD aged, they became more vulnerable to negative community influences and had fewer supports to advocate for their needs. Some parents noted that factions within their communities viewed children with FASD as not having disabilities but rather saw them as willfully bad and/or out of control. Community systems, as a result, become less supportive. Families note their children were labeled as troublemakers and invitations to participate in a meaningful way dwindled while invitations from troubled youth increased. This forced many families to take on additional responsibilities first as advocates and then as the sole support system for their children. These problems were often more exasperated as their children aged toward adolescents. Because of their poor social skills many of these children often felt alienated and bored in school and within the community. Many gravitated towards negative elements within the community and as a result associated with individuals and groups that used alcohol and drugs heavily.

While the challenges are many, Jones notes that there are also protective factors that have shielded youth with FASD from negative factors. The protective factors for one particular child was identified as being the youth's personality and his ability to maintain relationships both within the home and outside within the community coupled with a high level of parental guidance from his foster parents helped reduce some of the risks experienced by this particular adolescent with FASD. Jones (2004) notes that future studies might want to look more specifically at the rates of foster home breakdown for children and youth with FASD. An additional area of exploration would be issues related to the vulnerability of children with FASD that struggle with making and maintaining emotional relationship with others.

Gammon (2000, 2002)

Another Manitoba specific study focusing on the experiences of foster mothers caring for adolescents and young adults affected by prenatal exposure to alcohol was conducted by Gammon (2002). Sixteen foster mothers caring for adolescents and adults affected by FASD were interviewed about their experience caring for these individuals and to ask the question "How do we reduce stress for foster/adoptive mothers in order to create more stability and health for both these woman and the persons affected by prenatal exposure to alcohol?" Gammon notes that for many of these mothers, in their commitment to the children with FASD that they foster, gave up careers and job opportunities to be at home full time to care for these children. Incredible loneliness, isolation from family and friends and severe personal health problems connected to the stress of parenting teens/adults with FASD were observed as being among many of the stresses and challenges experienced by these mothers. Not getting respect and given credibility for the knowledge and experience gained through years of parenting persons with FASD was highlighted as some of the experiences noted by the mothers in this study. Some of the biggest stressors identified by these mothers were traced to the systemic barriers to



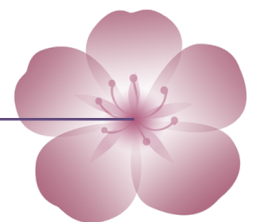
accessing services from the medical, educational, judicial, child welfare and adult service systems. Mothers in this study felt that a large majority of professional working in these system lacked training and education about FASD. The issue around lack of respect by professionals was also noted by Brown and Bednar (2001) when they reported on the challenges birth, foster and adoptive parents experienced in caring for children and adolescents with alcohol-related disabilities.

Brown, et al. (2001-2008)

Equally important to the issue of service needs of foster parents is the success linked to foster parents' perspectives on the placement of children in their care. Foster parents indicate that to have successful foster care placement, they needed to have the right personality and skills to foster, information about the child, a good relationship with the fostering agency, individual services, community support, linkages to other foster families, support from immediate and extended families, as well as self-care skills (Brown 2008). Brown and Campbell's (2007) research on foster parents' opinions regarding successful placements reiterated what is generally already found in the literature in that successful placements include knowing the child is living in a secure environment, maintaining children's connection to birth families, seamless agency involvement, that the child grows and that the foster placement "does not break down." Foster families also indicated that what they contribute as caregivers also is important to successful foster placements. Of particular note, the parents in this study highlighted the importance of the connection between birth and foster families for children in care. Foster parents in this study saw the birth family as important people with ongoing involvement in the lives of their children while they were in care. Brown and Campbell noted that while the majority of research focuses on permanent care (e.g. adoption) or family reunification as successful outcomes for foster placement, the data from their study challenges the necessity of an either/or outcome. Foster parents in this study felt their role and relationship with the child continuing long after the placement was over, when the child returned to his or her birth family and community. For birth families dealing with children affected by alcohol this is an important point and one that would be helpful to birth families in maintaining a sense of security for children with FASD who have experienced foster care placement. Foster families and vice versa would be helpful in providing respite care for all the families involved with alcohol affected children. Maintaining connections to the families of origin for children in care may be one essential factor in helping the retention of qualified foster parents

Beyond these studies, very little is known about the needs of the foster and adoptive parents who take on the task of raising children with FASD or what motivates these individuals to foster or adopt children with alcohol-related disabilities. The challenge of maintaining the personal health of caregivers, while evident in the research conducted by Brown et al (2007) with caregivers, is largely absent from the literature. What is also less apparent from the literature is how biological children of caregivers might be affected and impacted, negatively or positively, by their parents' decision to raise children with FASD.

Research does exist in the American context on service needs of families who care for children with disabilities (Sloper, 1999) or special health care needs (Shelton, 1987). However there is not a lot of Canadian research readily available regarding FASD and respite services, but it is well recognized that parents/caregivers of FASD children need respite, and that these parents/caregivers may be underrepresented in the current respite programs available and operating through child and family and other collateral community services. Foster parents have a difficult job in providing care for children



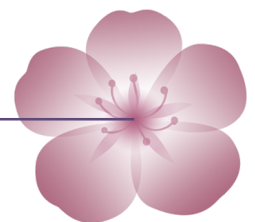
with or without disabilities and may need a variety of supports and services. Christian (2002) identified these as including:

- Adequate pre-service and in-service training;
- Information about the child, including the child's current case plan, educational and medical status, and placement and treatment history;
- Respect as a member of the child's case planning team and as a partner in the policy development process;
- Support from the child welfare agency, including adequate supervision, monitoring and consultation, as well as support from a network of other foster parents who can serve as mentors;
- An opportunity to provide feedback to the agency without fear of reprisal;
- Clarity about birth and foster parents' roles, rights and responsibilities;
- Services such as child care, respite care, liability insurance, and health care.

Understanding what motives foster parents to raise children affected by alcohol-related disabilities was explored by Brown, Sigvaldson and Bednar (2007). Their findings suggest that foster parents are motivated to care for children who have FASD when they witness positive change in these children as a result of their care. The desire to nurture children facing multiple challenges is often reported by foster parents as a motivating factor and simply because they wish to contribute to positive development in children with this disability and feel prepared to make that commitment. There is a sense of responsibility or duty because these foster parents also are aware that there is a shortage of suitable placements or because they know a particular child is in need. Other reasons for fostering children with FASD are related to earning an income, helping children stay connected to their families and communities of origin. The reasons for fostering children with specific alcohol related disabilities are similar to the reasons why other parents foster children with a range of special needs.

The challenges of raising children with alcohol-related disabilities were also identified by Brown and Bednar (2004). Managing and preventing setbacks in children's behaviour, finding time for themselves, making and keeping immediate and longer-term goals for their children, collaborating with schools, and keeping the child with FASD and their families involved in social activities, as well as being heard by professionals were the challenges that emerged from a concept mapping research project done with parents in a central prairie province. Concept mapping is a technique for visualizing relationships among different concepts. In Brown and Bednar's research concept mapping was used as a tool in defining the quantitative analysis of qualitative data provided by nineteen birth, foster and adoptive parents in asking the question "what are the challenges you face parenting a child with a fetal alcohol spectrum disorder?"

Using concept mapping again, Brown, Bednar and Sigvaldson (2007) delved further into the causes of placement breakdown among foster children affected by alcohol. Foster parents in that study reported that they might end the foster placement of a child with FASD if the child's behaviour problems became unmanageable despite different attempts to make the placement work or if the child posed a threat of harm to the others living in their home. Other specific reasons for ending a placement would be because of burnout, from demands that are too high or a lack of necessary resources. Parents also reported they would end a placement if they had not been given enough information or if they felt they were being



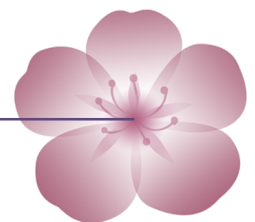
taken for granted. Brown et al indicate that the findings from their study have implications on efforts to retain foster parents who provide valuable care for children who have alcohol-related disorder. Understanding these issues is important in determining the most effective ways to avoid unnecessary foster placement disruptions for children who are FASD affected. It is clear that more research needs to be undertaken in this area.

Other Research

Mason and Linsk (2002) and Vig and Kaminer (2002) conducted research on the needs of parents where it was found that providing counselling services for parents who foster children with disabilities is beneficial. Crisis intervention and support was also noted as being specifically helpful to foster parents by Hudson and Levasseur (2002). Families caring for children with disabilities report significantly lower stress levels following respite care and it was generally agreed that regular time away from the children for physical, emotional and social reasons is crucial (Hudson & Levasseur, 2002). Canadian research conducted by Brown, Moraes and Mayhew (2005) provided insight in the service needs of families who foster children with disabilities. The major services identified by parents in their study identified the need for: support in the community, financial support, accommodating schools, good relationships with social workers, responsible professionals, information, comprehensive medical care, services for Aboriginal children and families, transitional services, and respite. And while their research focused primarily on children with disabilities, the findings are just as applicable to the service needs of families that provide care to children with alcohol related disabilities.

Morrisette (2001) noted there was a dearth of information on the lived experiences of foster/adoptive parents raising children diagnosed with FASD. To fill the void in the literature, Morrisette conducted a study with parents raising children diagnosed with FASD and based on the results suggested ways that family counselors could intervene to help families in these situations. Morrisette recruited parents who were actively parenting children with FASD and who were willing to share their experience and illuminate on this experience. Interviews were conducted with a small sampling of 6 parents who had an average of 10 years parenting children with FASD. The interviews yielded seven predominant themes: (a) constant vigil; (b) effects on marriages; (c) child management; (d) parental issues; (e) interactions with professional community; (f) emancipation concerns; and (g) medical implications.

Based on these findings, Morrisette identified three roles, which family counselors could assume in working with foster/adoptive families who care for children diagnosed with FASD. These three roles were identified as being a clinician, facilitator and researcher / educator. A clinician was identified as being useful to parents as FASD symptoms are not always detected or understood and without an explanation or remedy for their child's behaviour, parents can find themselves experiencing self-doubt and embroiled in marital disputes regarding child management strategies. Due to their knowledge about child development and parent-child issues, family counselors can intervene, suggest effective behavioural management strategies and provide on-going support to parents and families. For parents in particular, providing care for children diagnosed with FASD can have a negative impact on their daily parenting efforts, personal well-being, and overall marital relationship. If left unattended these issues can fester, transcend the couple and affect the entire family system and can set back any progress made by children impacted with FASD. Morrisette also notes that to reduce stress, worry and confusion counselors can act as facilitators to help in facilitating informational meetings with parents and

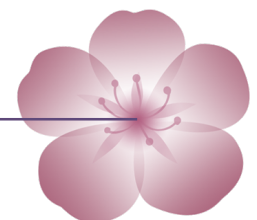
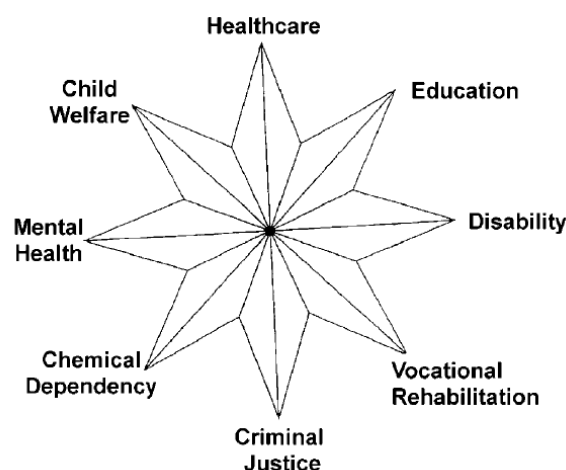


connecting them with resources and facilitating collaborative relations with others (e.g. teachers, social workers, physicians, etc.). Lastly, the role of researcher / educator was identified by Morrisette as being another important role for family counselors working with families who have children with FASD. Morrisette states that:

Counseling research can also be directed toward gaining increased insight into the structure and functioning of foster/adoptive families who raise children diagnosed with FASD. Future research ideas include investigating the differences between rural and urban families, the contrast between single and dual parent families, and the effects of caring for children diagnosed with FAS on caregivers' biological offspring. To decrease parental isolation, frustration, and trepidation research findings can be disseminated to both professionals and parents through appropriate sources. As more data is gathered, services can be designed, implemented and investigated to assist parents and children diagnosed with FAS. Considering the unique needs of parents and caregivers, family counselors because of their specialized training and related skills are in a good position to help families raising children with FAS in better understanding the systematic effects of this syndrome.

Understanding the stress of parenting children with FASD was identified in research published by Paley, O'Connor, Frankel and Marquardt (2006). Biological parent status and fewer family resources were associated with higher levels of parent stress. They note that adoptive/foster parents in particular have higher levels of child-related stress than did biological parents. One of the reasons for this, they explain, is that adoptive/foster parents "may not have been adequately prepared for the severity of their child's difficulties, particularly as some were initially unaware of their child's prenatal exposure to alcohol, whereas others may not have been fully cognizant of the potential risks of prenatal exposure of alcohol before bringing the child into their family" (p.401). Paley, et al note that stressed parents may behave in ways that contribute to their child's difficulty as the relationship between child functioning and parenting stress is likely a reciprocal one. Their research reiterates the need to provide support not only to children with FASD but to their caregivers as well.

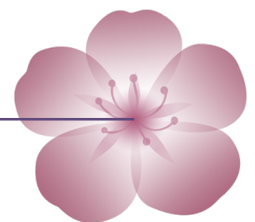
A system of care was conceptualized in research conducted with parents by DeVries and Waller (2004). Such a system was conceptualizes an organized intervention system which includes all the service systems outlined in the following diagram. This service system would provide "intervention touchpoints" where eligibility criteria is designed to include, not exclude, children, adolescents, and adults with FAS/E, especially those with normal IQs.

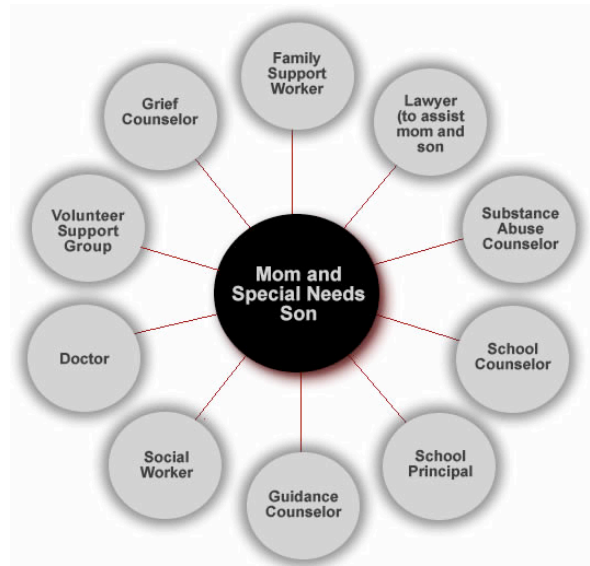


Source: FAS/E Intervention Touchpoint System, (DeVries & Waller, 2004), p. 124.

A similar intervention system that is cognizant of the multiple aspects to the FASD continuum was also conceived by Della McGuire, a First Nations Woman who has conducted training sessions, workshops, and conferences on Fetal Alcohol Syndrome across Canada for over 12 years within Aboriginal communities. McGuire stated that those who aren't touched by FASD, or who don't hear about it, don't realize how stressful and how alone people and families feel (Bennett & Shangreaux, 2007). In order to understand this point, Della asked the audience to participate in a demonstration of what a mother would experience when her son had been recently been diagnosed with FASD and was in trouble with the law. One person was asked to volunteer to be the mother while others volunteered were asked to read a card to the volunteer mother. The volunteers representing the professionals in this exercise ideally show how they could be assisting parents in understanding what would happen next given her child's diagnosis and how this might put him/her in trouble with the law. Those professionals were identified as being a:

- ✓ **Grief counselor** (referred to by doctor who diagnosed her son; mother can call anytime for assistance);
- ✓ **Volunteer** for a support group in the community;
- ✓ **Family support worker** for FASD program (support to mom and family, provides information about FASD; travel);
- ✓ **Doctor** (regular appointments and monitoring medications for son);
- ✓ Other children of mother (expressing disappointment about how much attention mother gives to son);
- ✓ **Social Worker** (checking in regularly but also extending support to mom at any time);
- ✓ **Lawyer** (representing son and procedures for court);
- ✓ **Substance abuse counselor** (will see the son once a week);
- ✓ **School counselor** (assisting son once a month);
- ✓ **Principal of school** (ensuring son has all the help and resources he needs);
- ✓ **Guidance counselor** (helping him pick courses to help him plan for future);



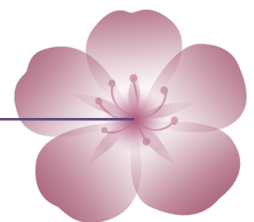


Source: Bennett and Shangreux, 2007, p. 7.

Guidance Resources for Parents with Children Affected by FASD

Until recently, recently very little information was available to birth, foster or adoptive parents about how to raise or what to expect from children who were alcohol effected. One of the foremost experts on Fetal Alcohol Syndrome is Dr. Anne Streissguth who, in 1997, published one of the first guidebooks geared toward parents and caregivers with children affected by FASD. In *Fetal Alcohol Syndrome: A Guide for Families and Communities*, which used case studies, photos, illustrations, and validated empirical research, the author highlighted the cultural, racial, and economic diversity of FAS. The purpose for writing the book was a hope that the thoughts, ideas and strategies presented would be helpful to parents and caregivers of children with FASD. The information presented in the book also acknowledges that the suggestions could be helpful to not just children diagnosed with FASD but would be helpful to many other children who are not diagnosed with FASD.

Since then, numerous resources have been developed out of various information forums held across Canada with birth, foster and adoptive parents and caregivers dealing with children, adolescent and adult children with confirmed and suspected FASD. One particular forum held in British Columbia, *Fighting for a Future: FASD and 'the system': adolescents, adults and their families and the state of affairs* (prepared by Jan Lutke and Tina Antrobus, 2004) highlights relevant needs and issues facing adolescents and adults with FASD in today's society. The resulting report reflects on service delivery models and services which parents and caregivers believed from their personal and professional experiences would enhance support for individuals with FASD and their families. The report focuses on six key areas highlighted as being of specific importance for meeting the needs of individuals with FASD: (1) housing and homelessness; (2) finances; (3) health and mental health; (4) education, programming and employment; (5) legal and addictions; and lastly, (6) family support. In discussing these six areas, participants in the forum also addressed (a) what needs are specific to the issues; (b) what gaps exist in

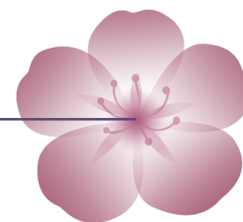


services to address the issue; and (c) recommendations for action. The discussion resulted in broad recommendations identified for the six key areas:

- Safe, stable, secure, supported, structured, supervised, subsidized housing (7S model) should be considered the primary key to broad risk management for adults with FASD. The absence of housing is the absence of everything;
- The deployment of financial resources specifically targeted at FASD service delivery should be undertaken and considered a primary broad risk management tool for working with adolescents and adults with FASD;
- The development and funding of targeted health care delivery and mental health treatment should be considered as a primary broad risk management tool for working with adolescents and adults with FASD. The provision of funded long-term mental health care to parents and other family members should be available, funded and encouraged as a risk reducing tool in the maintenance of essential supports to individuals with FASD;
- The development and funding of targeted educational, vocational, employment and other programming that is specific to adolescents and adults with FASD should be considered as a primary broad risk management tool. It should also be considered as a risk reduction tool in its ability to help maintain both residential and family placements and to provide 'respite' to parents;
- Involvement with the legal and addictions systems occurs when other risk reduction strategies have been ineffective for a variety of reasons. However, because it is in the position of having to provide services to individuals with FASD regardless, it could also provide a pivotal intervention point. The development and funding of targeted legal and addiction services that are specific to adolescents and adults with FASD should be considered as a primary risk management tool;
- The development and funding of consultative processes that have the authority to direct, monitor and evaluate changes specific to the support needs of adolescents and adults with FASD and the particular needs of their families should be considered as a primary broad risk management tool.

Many other resources have been developed offering help and guidance to families and caregivers parenting children affected by Fetal Alcohol Syndrome. The following listing is a sampling of some of the parenting resources found that cater to addressing the needs of parents and caregivers living with children and youth with FASD. This is not a comprehensive list:

- Normand, C. L. & Rutman, D. (1996). Caring for Children with Fetal Alcohol Syndrome. Child, Family & Community Research Program, School of Social Work, University of Victoria.
- Rutman, D. & Normand, C. L. (1996). Working with Families Affected by Fetal Alcohol Syndrome/Effects. Child, Family & Community Research Program, School of Social Work, University of Victoria.
- Streissguth, A. (1997). Fetal Alcohol Syndrome: A Guide for Families and Communities. Paul Brookes, <http://depts.washington.edu/fadu/>.
- Graefe, S. (1998). Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living (2nd Edition -- Revised and Expanded). Vancouver, British Columbia: The Society of Special Needs Adoptive Parents. Vancouver, B.C. Retrieved from: http://www.mofas.org/download_files/parents_guide.pdf.



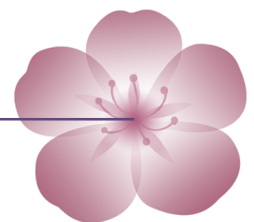
- Badry, D. E. & Lawryk, L. (Eds.) (2000). Letters to Our Children, Letters From Our Children: Living with Fetal Alcohol Syndrome and Alcohol Related Effects. Alberta Assoc. for Community Living. Calgary, Alberta.
- B. C. Aboriginal Network on Disability Society (Ed.) (2001). A Practical Native American Guide for Caregivers, Adolescents and Adults with Fetal Alcohol Syndrome and Alcohol Related Conditions. Victoria, B.C.
- Tudeau, Debbie. (Ed.). (2002). Trying Differently: A Guide for Daily Living and Working with FAS and other Brain Differences (2nd Ed.). Yukon: Fetal Alcohol Syndrome Society Yukon.
- Buxton, B. (2004). Damaged Angels: A mother discovers the terrible cost of alcohol in pregnancy. Knopf Canada.
- Graefe, Sara. (2004). (Ed.). Living with FASD: A Guide for Parents. British Columbia: Special Needs Adoptive Parents. Groundwork Press.
- Jones, S. and Cunningham, L. (2004). FASD Strategies, Not Solutions. Edmonton, AB: Region 6 Edmonton and Area Child and Youth with FASD Sub-Committee. Retrieved from: <http://www.region6fasd.ca/pdfs/FASD%20Region%206%20-%20Strategies%20Not%20Solutions.pdf>.
- Wake Forest University, School of Medicine. (2004). Fetal Alcohol Syndrome: A Parent's Guide to Caring for a Child Diagnosed with FAS. Winston-Salem, North Carolina: Wake Forest University Health Sciences. Retrieved from: http://www.otispregnancy.org/pdf/fas_booklet.pdf.
- E. Froehlich, M.Ed. and A. Bournnonniere, M.Ed. (2005). Talking with Parents about Raising Children with Fetal Alcohol Spectrum Disorders. Child Guidance Clinic.
- Wemigwans, J. and Cunningham, M. (2005). FASD Tool Kit for Aboriginal Families. Toronto, ON: Ontario Federation of Indian Friendship Centres. Retrieved from: <http://www.accel-capea.ca/pdf/FASDToolkit.pdf>.
- VON Canada. (2006). Let's Talk FASD: Parent Driven Best Practice Strategies in Caring for Children and Adults with FASD. Ottawa, ON: Victorian Order of Nurses VON Canada. Retrieved from: http://www.von.ca/FASD/_fasdtool_fullproof_final.pdf.
- Rajwani, C. (2008). Strategies parents find helpful in raising their children living with FASD. Toronto, ON: St. Michael's Fetal Alcohol Spectrum Diagnostic Clinic. Retrieved from: http://www.asantecentre.org/_Library/docs/Raising_Children_Living_with_FASD1.pdf

Parents with FASD

Parents with FASD have trouble with critical skills that parents should have, so their abilities to raise children are often called in to question (Abraham, 2006). Parents who themselves were prenatally exposed to alcohol may or may not have been diagnosed with FASD. This population has difficulty with parenting for several specific reasons:

- Inability and/or lack of ability to bond with their children;
- Poor memory; and
- Poor problem solving and anger (Grant, Ernst, Streissguth & Porter, 1997).

Issues faced by parents with FASD are because of the organic brain damage they suffered in vitro. As a result parents with FASD may not be able to bond with their children. Adult parents with FASD may appear to neglect their children because they may forget about their children, for instance, if they leave them outside to play while they run in to answer the phone. Parents with FASD may also forget to feed, clothe and bathe their children. Poor memory can mean that children don't get basic medical care and or they may not get to school. Parenting requires being able to multi-task but for people with FASD, they are limited in this area. Adults with FASD have poor problem solving skills and may become easily



agitated which can trigger abusive situations for the children in their care (Rutman, La Berge & Wheway, 2005). Anger management programs tend to be cognitive based and will not work for people with FASD. Frustration is increased because people with this disability understand that they are not doing what needs to be done but can't seem to improve the situation). Often children are removed from the home and while the parent will do what is necessary to have the children returned, he or she never quite "gets their act together" (Grant, Ernst, Streissguth & Porter, 1997).

As with individuals in the general population, individuals with FASD also become parents but research on the challenges faced by adults with FASD who are parents is very limited and perhaps almost non-existent within the Canadian context (Harriman, 2007). The issue of parenting with FASD was explored by Deborah Rutman and colleagues Corey La Berge and Donna Wheway in British Columbia. A research and production of a video on the challenges, strategies and supports for parenting with FASD were published in 2005. Many of the challenges faced by parents with FASD relate to the secondary disabilities or to conditions and life experiences that affect a disproportionate number of parents who have FASD. The secondary disabilities experienced by parents with FASD include:

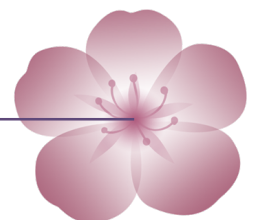
- Drug and alcohol use / addiction
- Abusive or fragile domestic situations
- Transience and homelessness
- Not having positive role models
- Poverty, lack of resources and social supports
- Child may have learning difficulties and or special needs (Rutman, La Berge & Wheway, 2005, p. 10-12).

In addition to the challenges faced in parenting, individuals with FASD must also contend with an array of misunderstandings from society in general. These include:

- Feeling stigmatized and prejudged by service providers and the public at large;
- The invisibility of FASD as a disability (many people over-estimate the abilities of a person with FASD with the result that expectations become unrealistic and impossible to meet) (Rutman, La Berge & Wheway, 2005, p. 12-13).

Other areas where parents with FASD are vulnerable include being a victim of abuse or being taken advantage by family and/or friends (Rasmussen & Wyper, 2007; Kelly, 2003).

UNBC graduate student Velma Abraham also studied the perspectives of adults with FASD who go on to become parents themselves for her Master's degree (2006). Abraham interviewed service providers and parents in Prince George to explore the needs of adults who face the dual challenge of parenting and living with FASD. Three thematic categories emerged from her research findings: (i) parental needs, (ii) desirable services and support, and (iii) barriers to service delivery. Her study illustrates that parents with FASD require appropriate support and service in a number of areas such as transportation, child care, social benefits, and adequate housing. There is a pressing need to develop these programs. Currently, most programs are not specifically developed to meet the needs of parents with FASD; doing so would require that services be individually oriented, ongoing and long-term, proactive, and

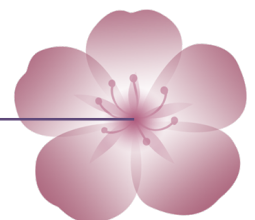


empowering. Parents with FASD face barriers to service delivery in part because there is a lack of trained service providers and inadequate funding. Abraham states it's too easy for parents with FASD to fall between the cracks. Abraham's research indicates clearly the need for alternative or new service models that meet the needs of parents with FASD.

Most parents affected by FASD love their children dearly, and some people affected by FASD are known for their considerable ability to care for others (Harriman, 2007). However, many parents affected by FASD require ongoing support to parent effectively. The neurological damage caused by in utero exposure to alcohol causes life-long brain dysfunction that can affect judgment, decision-making, and social behaviours, including parenting behaviours. Parents affected by FASD might need social support to perform basic parenting tasks such as getting children to bed and ensuring children are fed regularly. They might also need legal assistance, financial support, drug and alcohol treatment, mental health services and companionship (Abraham & Hardy, 2006). Some parents affected by FASD lose custody of their children due to child protection concerns, and after apprehension, some parents encounter severe challenges in meeting the conditions for family reunification (Harriman, 2007). Parents whose cognitive abilities have been adversely affected by FASD may have trouble understanding why their children have been apprehended. They may not comprehend, let alone have the capacity to meet, the conditions imposed by child protection services (Harriman, 2007).

It must also be noted that while parents with FASD may have difficulties with memory, time, scheduling, money, bill paying, and budgeting, many of them also have strengths in these areas as well and are very competent. Not everyone affected by FASD has the same types of difficulties or deficits in functioning, and people's difficulties or deficits occur in varying degrees (Rutman, La Berge & Wheway, 2005). It is important to explore with parents to identify their needs and help the family plan goals around these needs. Services providers must also be cognizant that parents with FASD may become overwhelmed if they deal with too many people or they are tasked with too many expectations. They may shut down, become angry, or otherwise overreact to situations and lose trust as a result. Individuals who have FASD have had a history of continuous negative feedback can become discouraged and avoid social interactions. Without respect, trust and ability to see the person's strengths, service workers may find it difficult to work with alcohol-affected individuals. At the same time, service workers need to rethink issues that relate to the independence of parents who are alcohol-affected. The FAS Toolkit written notes that many workers have been cautioned at times to avoid making families too dependent on them. This puts many parents with FASD in a difficult situation as there are likely many activities that they cannot manage unless they have help from others. FASD makes being independent near impossible and persons in the helping profession may not understand this dilemma. Parents with FASD may need help that other parents may not need. The FAS Tool Kit authors indicate that workers need to be very patient and avoid adding to the difficulties already being experienced by parents who are compromised as result of being alcohol affected. Understanding the needs of parents who are alcohol affected will require service workers to be flexible and open to new and very different ways of helping families (FAS Toolkit, no date).

The importance of supportive practices and access to supportive service providers for individuals parenting with FASD were explored by Rutman, La Berge and Wheway (2005). They note that the presence of supportive practices that help to act as "protective factors" from the secondary effects of



FASD, particular those that could affect child welfare (e.g. loss of custody/child apprehension). The types of supportive practices identified by Rutman, La Berge and Wheway (2005) include:

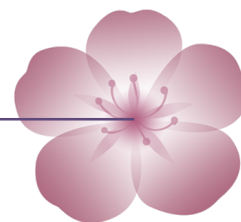
- Immediate on-call support – having someone available 24/7 to answer questions, provide support, assistance, and advice
- Ongoing support that is long term
- Support that is individually tailor to peoples' individual needs
- One to one support (hands-on and experiential learning)
- Outreach (efforts to reach out and stay in touch with the parent affected by FASD)
- Practical support and assistance with tasks that require 'abstract' thinking (e.g. helping with tasks that require executive functioning or abstract thinking that involve setting up appointments, translating difficult information into clear, concrete and concise steps)
- Being non-judgmental and non-condescending
- Focus on strengths rather than the parent's problems and inadequacies
- Healthy role models (having support people who have healthy life styles) (p.25-30).

Having supportive practices and access to supportive service providers have a number of positive outcomes for the individuals who are parenting with FASD cognitive disabilities. Rutman, La Berge & Wheway, 2005 note that some of the positive outcomes include:

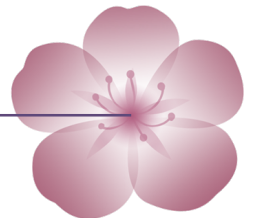
- Improve self-esteem and self-confidence
- Improved personal and parenting skills
- Improved treatment from and relationships with service providers
- Positive outcomes regarding the child welfare system (p. 32-34).

Rutman, La Berge and Wheway (2005) also identified a number of other approaches that would help in producing better outcomes for families affected by alcohol-related deficits. Instead of "trying harder" they indicate a need to "try differently" or "thinking the way they think" when working with parents who are affected by FASD. Trying differently means realizing that there is cost effectiveness to implementing supportive services for adults/parents who have FASD and investing in community-based supports now rather than later. Another area where they identified a need for a fundamental shift in thinking and practice is in the implementation of different child welfare policies that allow families to access supportive services without that access being contingent on involvement with the child protection systems. Central to trying and thinking different also, is "getting to know people as individuals and appreciating their unique capacities, needs and the strategies they use to navigate their day to day world. Recognizing the degree of diversity across FASD affected adults, and thus tailoring programs and practices accordingly, is at the heart of this approach" (p.37). The need for community and professional education regarding FASD is needed and should be grounded in individuals' lived experiences which involve affected adults and includes the people in their supportive networks as both educators and/or presenters. Rutman, et al, indicate that this approach would contribute to community development, wellness and healing as well as the prevention of FASD (p.38).

Parents who have children with FAS are often the ones with the most in-depth knowledge. They are the ones that work to strengthen families and they are often the ones that push policy forward—they have



been expressed by experts in the field as the real professionals (Gammon, 2002; Jones, 2004; Lawryk, 2005). Parents, whether they are biological, foster or adoptive, are the main advocates for FASD affected children and adolescents and they need assistance to carry out the difficult but important task of raising children and adolescents who are affected by FASD spectrum of disabilities. This is a lifetime disability and their role as the “external brains” for these children and adolescents won’t likely subside even long after the children and adolescents in their care reach the age of majority.



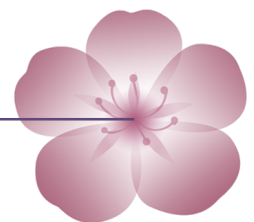
Section 4 – Pregnant Women at High Risk of Misusing Substances and Involvement with Child and Family Service Systems

Overview:

- A tremendous volume of literature revolving around Canadian women of child bearing age and alcohol use during pregnancy and the awareness of risk;
- Two specific groups of women at risk: (1) Women over 30 years with careers who report consuming alcohol during their last pregnancy and; (2) women who use other substances, have low self-esteem, who are young, poor, unemployed or depressed and at high risk as they may need substantial care and support to address their alcohol use;
- Majority of the research focuses on child welfare involvement with families dealing with alcohol addiction;
- Very few of these resources specifically on the point of women at high risk of misusing substances and subsequent involvement with child welfare although within the discourse researchers have identified why women might not consider accessing treatment for their addiction issues – fear of child welfare involvement and the possibility of losing children because of their substance abuse are frequently cited as being one of many reasons why there are higher incidences of children born with FASD;
- Key area for understanding this issue stems from a decision made by the Supreme Court of Canada on the case of Mrs. G. from Manitoba. Analysis of this case has focused on assumptions and ideologies around standards of motherhood and perspectives in the media that women who use substances are abusive and bad parents. Drinking while pregnant is viewed synonymously with child abuse and hence a reason to apprehend children. The discourse that emerged from these cases tends to focus on the rights of women versus the rights of fetuses. The Supreme Court ruled that a fetus is not a person until after birth. As a result, prosecution for women who are misusing substances during pregnancy cannot happen because fetuses do not have legal rights or status under Canada's Criminal Code. Rights of fetuses need to be developed in legislation but thus far this has not happened in any jurisdiction in Canada;
- In the US, states have implemented ways to circumvent mothers from continuing to harm their babies during pregnancy – authorities have turned to other reasons which would allow court to jail the mother thereby removing her from the environment in which the harm is happening.

Sample of search terms used:

- FASD prevention with pregnant women involved with child welfare
- Pregnant women with substance abuse and child welfare involvement
- Child welfare and pregnant women who misuse substances
- Child welfare and substance abusing pregnant women
- Child welfare intervention with pregnant women who have addictions
- Pregnant women, addictions and child welfare interventions
- Perinatal addiction, child welfare intervention and advocacy
- Perinatal addiction and child welfare intervention
- FASD affected mothers and child welfare
- Working with at-risk pregnant women
- Prenatal substance exposure and child welfare involvement
- Prenatal substance exposure and child welfare authority
- Chemically addicted mothers and child welfare
- Substance addicted mothers and child welfare
- Pregnant, Alcohol-Abusing Women

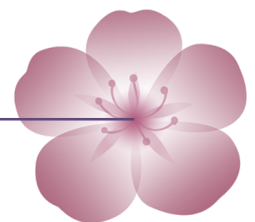


- Access to treatment for pregnant women with addictions appears to be problematic as there are many services in each province that offer treatment but few programs may be women centred or operate through harm reduction approaches. Overall there are few programs that cater to pregnant substance using mothers.

The Discourse on Mothering

Mothers, who use substances, particularly when pregnant, have come under intense scrutiny in Canada in recent years. To understand the involvement of substance-using and pregnant women with the child welfare system, one must look to the discourse that emerged as a result of the 1997 Supreme Court decision regarding Mrs. G, a solvent addicted Aboriginal woman, who was pregnant with her fourth child (*Winnipeg Child and Family Services (Northwest Area) v. G (D.F.)*). *Winnipeg Child and Family Services (W.C.F.S.) v. G.(D.F.)* was the infamous “glue sniffing” case that pitted the rights of the mother against the rights of the unborn child (Cull, 2006). Winnipeg Child and Family Services, a child welfare agency in Manitoba, sought to detain the mother for the duration of her pregnancy to protect her fetus from any developmental impacts that might arise because of her addiction (Buydens, 2005; Cull, 2006). The media was merciless in its portrayal of the mother as a selfish villain, she was the antithesis of the “good” mother, a “toxic mother” (Buydens, 2005). Cull (2006) notes that she was stigmatized, demonized, and ostracized. Lost among the facts was that the mother in question had voluntarily entered a treatment centre and that earlier in her pregnancy, she had sought treatment but was turned away due to lack of facilities (Tait, 2001; Cull, 2006). She was portrayed as a “fetus abuser” and not as a woman who had a long history of trauma who was struggling with addiction and who was in need of and actively seeking help in an effort to create a better life for herself and her child.

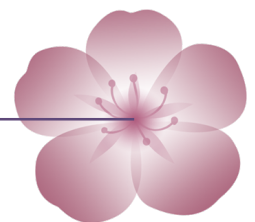
Ms. G was declared mentally incompetent to make her own decisions, and was placed under the care of the Winnipeg Child and Family Services, based on the argument that her actions violated the “duty of care” owed to her fetus. At the Manitoba Court of Appeal and, later, on appeal at the Supreme Court of Canada, this decision was overturned. The public discourse on women as mothers as users of alcohol, drugs and tobacco are fundamentally judgmental, blaming and unsympathetic. As in the Ms. G case, it has usually presented women as mothers in an adversarial position to the rights of their children and rarely makes mention of any role men as fathers or partners, supportive or otherwise, may have in the situation. Canadian researchers have illustrated how race and class intersect with women’s health and substance use (Buydens, 2005; Cull, 2006). Among them, Susan Boyd (1999: 26), whose research focuses on the negative stereotyping of substance-using mothers, underlines how “in Canada, First Nations women, poor women and single mothers appear to be over represented in terms of arrests, child apprehensions and medical interventions”. The Supreme Court case involving Ms. G, “a young woman marginalized by her indigence, her status as an Aboriginal, by her repeated pregnancies, and by her general physical health” became a national example of this pattern (McCormack 1999: 79). The case of this substance-using mother “became part of the backlash against welfare expenditures and welfare dependency, while evoking racist stereotypes of native people” (McCormack 1999, p.81; Buydens, 2005; Cull, 2006). Tait (2001) notes that the moral gaze on substance using Aboriginal women in particular masks the colonial impacts reflected in the social, economic and political ramifications that are evident and still existing as a result of this Canadian history.



Mother bashing, as evidenced in the media coverage of Mrs. G., became a media favored activity noted Greaves, Varcoe, Poole, Morrow, Johnson, Pederson & Irwin, 2002 [hereafter Greaves et al, 2002]. Their study looked at the discourses on women mothering under duress which originated from a growing concern about the reduced importance of mothers. Their report, published through Status of Women Canada, examined current approaches to mothering in Canada as articulated through key policy documents, media portrayals and through interviews and focus groups conducted with over 50 women. In particular, Greaves and her colleagues examined 3 types of mothering under duress situations: (1) mothers who use substances; (2) mothers with mental health issues, and; (3) mothers who have experienced violence in domestic settings. A focus on mothering in the Province of British Columbia, in particular, factored significantly into their analysis. It is not surprising that many of the examples they analyzed were culled from many high profile cases involving Aboriginal and First Nations women mothering under duress. The authors used three interconnected concepts — rights, risk and evidence — to analyze the trends in relation to the 3 types of mothering under duress situations. All three of these concepts (rights, risk and evidence) are directly or indirectly used in developing and perpetuating discourses on mothering and on mothering under duress. Their general findings indicate that while mothers in each of these situations are portrayed differently at times, there are similarities. For instance, the authors found that mothers who use substances are considered responsible for their situation, while mothers who have mental health issues are felt to have no control over theirs. In between, the mothers experiencing violence were considered to be partly responsible. Moreover, the authors note that these three situations are increasingly framed as concerns of child welfare:

While frequently an important concern in these situations, the focus on child welfare overlooks and obscures the issues of women's welfare that precede or parallel the events. A tendency to overlook the factors affecting women or mothers in these situations may allow policy and protocol to develop that do not respect or enhance women's rights and, specifically, the rights of mothers. In addition, it obscures the critical interconnectedness of mothers and their children, by ignoring the importance of the relationship between the mother and child and the necessity to preserve, support and maintain it. Consequently, many aspects of the solutions or treatment of problems, such as substance use, mental illness or violence against women, fall short and deprive both mothers and children of the support required to work through periods of duress (p.4).

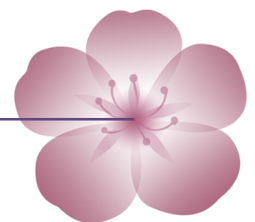
Greaves, et al. (2002) indicate that mothering has been reduced and subsumed into “parenting,” a gender-neutral (and potentially diminishing) concept that explicitly allows others to be considered “as good as,” or equivalent to, mothers. “It also allows for the introduction of alternate caregivers, often identified or paid by the state, who become seen as, if not a completely adequate replacement, then at least as important as the mother. These replacement custodians are critical to the operation of a child welfare system, but should not be at the expense of the mother and the mother–child relationship” (p.5). Much of this shift has been accomplished in the “best interests of the child.” This phrase has supported the logic behind much of the family law reform in Canada and continues to be the pivotal legal concept in the discourses surrounding mothering under duress, despite the term being critiqued for its vagueness and indeterminate nature (Crossman & Mykitiuk 1998, p. 31, as cited in Greaves, et al, 2002 at p. 5).



Aboriginal Mothers

In the articles related specifically to fetal alcohol syndrome, FAS was often linked to those who are disadvantaged and of Aboriginal descent (Tait, 2001). Canadian studies on women's use of alcohol during pregnancy, particularly in relation to Fetal Alcohol Spectrum Disorder (FASD), disproportionately focus on Aboriginal women (Masotti, Szala-Meneok, Selby, 2003 [hereafter Massotti et al, 2003]). Some research indicates that FAS is 10 times more prevalent in Aboriginal communities (Tait, 2001). Salmon (2007), quoting from a national survey conducted by Adlaf, Begin, Sawka (2005), showed that problem drinking is more prevalent among wealthy women with higher levels of education. Middle- and upper-class women's substance use is rarely constructed and responded to as a "social problem" requiring intervention from the state, and further, public education campaigns about FASD prevention rarely focus on this group of women (Salmon, 2007). Greaves et al (2002) note that such discourse serves only to continue to bring Aboriginal women under intense scrutiny for their substance use during pregnancy and as mothers, without bringing visibility to the current or needed supports (which do not currently exist in some of their communities) to assist Aboriginal women in improving their own health and the health of their families (Salmon, 2007). Furthermore Masotti et al (2003) note that the focus on Aboriginal communities with high rates of alcohol abuse and on regions with large concentrations of Aboriginal peoples means that Canada lacks epidemiological data regarding other populations, making it difficult to determine whether Aboriginal women are, in fact, at greater risk than other groups. Moreover, stereotypes of Aboriginal peoples as particularly prone to alcoholism or in need of intervention for problematic substance use can act as a barrier to care for some Aboriginal women who wish to disclose or seek support for substance use issues and well-being (Poole & Dell, 2004; Salmon, 2007).

As well, Tait (2001) has also noted that where mothers are receiving social assistance, it is likely that her behaviour has been documented during her child bearing years. Past problems with alcohol can likely be determined based on information contained in client files. This is particularly so for First Nations women, who have had their health and social histories documented in various government files, due to their longer history with governmental agencies and institutions (Tait, 2001). The data already systematically collected from First Nations communities is particularly concerning in that the "systems of surveillance that produce data about Aboriginal health are powerful social instruments for the construction of Aboriginal identity" (p.103-104). Moreover, the longitudinal health and social histories of reserve populations are relatively easy to access through school and other government health records making it attractive to researchers wanting to use this data to monitor maternal alcohol exposure in Aboriginal communities. Tait notes this is a disturbing trend for Aboriginal communities. As more Aboriginal communities become aware of FASD as a public health problem in their communities, they are becoming more inclined to embrace (or internalize) FASD as an explanation for certain realities they see in the communities they service. This overexposure leads many outsiders to draw false perceptions about Aboriginal populations and has ethical implications. In particular, Tait observed that the information collected from First Nations can be used to reinforce unequal power relationships where the "image of sick, disorganized communities can be used to justify paternalism and dependency" (p.105) and threatens the autonomy of Aboriginal peoples. She suggested that higher rates of FASD diagnoses among Aboriginal populations have been used by non-Aboriginal people as a way to discredit Aboriginal populations during self-government negotiations.



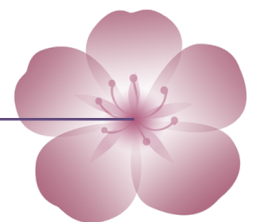
Much has been written by medical experts about FAS/E however, Loewen (2001) indicates that little has been written from a sociological perspective as the literature in this area tends to point a finger squarely at the Aboriginal mother yet her voice is absent from the literature. Social science research on the connection of fathers' to FASD, as Badry (2009) points out, lags behind with only one published study regarding the role of fathers (see Gearing, McNeill & Lozier, 2005). There has been a great deal of interest by the medical field in FASD especially in relation to First Nations peoples. As noted earlier, Badry (2009) states that the focus on Aboriginal women based on limited research has resulted in negative assumptions of a higher prevalence rate among First Nations than among other populations. First Nations communities have become reluctant to participate in fetal alcohol studies, especially since they usually reap little tangible benefit from having the lives of their women and children exposed. As noted by Fournier & Crey (1997), the publicity that accompanies such studies can be hurtful and counterproductive for all concerned. Such an occurred in 1985 when the University of British Columbia undertook a three phase study on FAS/E with the residents of Canim Lake, B.C. The research was aborted by the community because early results of the study led to sensational media headlines and other communities since have had similar experiences (Fournier & Crey, 1997). First Nations have concluded that they must take ownership and control of FASD research to ensure that future studies meet their needs first as well as combat denial and to develop culturally appropriate programs to service the needs of this special population (Irvine & Vincent, 2005).

Bell, Trevethan and Allegri (2004) examined the prevalence of FASD in a sample of Aboriginal women offenders and their children. Sixty Aboriginal women offenders were interviewed. Of the 60 women interviewed, nine indicated that they had been assessed for FASD while four were officially diagnosed with FASD. Almost two-thirds of these women reported that they knew children who might be affected by FASD and eight women reported that they will be caring for children who have FASD. The authors of this report underscore the need to conduct more research into the prevalence of FASD in the offender population and more specifically the Aboriginal offender population. They note that more specialized programs and services need to be provided to offenders affected by FASD while incarcerated in order to better facilitate their program participation and community reintegration. The authors of this report note particularly that,

Very few Aboriginal women have participated in programs or training related to caring for children with FASD, and of those children reported to be affected by FASD under their care, very few have participated in programs to deal with their needs. As such, community resources must be accessible to address this specific health concern, which includes encouraging Aboriginal women's participation in these services. This may include programs for children with FASD, counselling for families affected by FASD, and individual help and attention for children with FASD. Finally, community awareness and education are viewed as critical to both the prevention and intervention of FASD among Aboriginal peoples (Bell, Trevethan & Allegri, 2004, p. iii-iv).

Risk Factors

There are many risk factors faced by women that may predispose them to drinking in their child bearing years. Tait (2001) indicates that these can include:



- Engaging in binge drinking
- A long history of alcohol abuse
- A history of major mental illness
- A partner who drinks heavily
- History of heavy drinking in the family
- Lower socio-economic status
- A culture that tolerates heavy drinking
- Sexual dysfunction associated with increased levels of drinking and heavy drinking
- Never married, separated, or divorced
- Poly-substance misuse

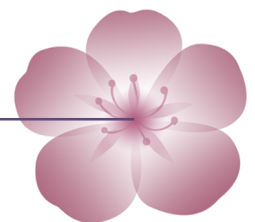
Being poor and Aboriginal have been identified as risk factors (Royal Commission on New Reproductive Technologies, 1993). This may be true for Aboriginal women in particular as the following risk factors are identified as occurring at higher rates:

- Sexual, psychological and physical abuse committed against Aboriginal women, either as children or adults
- The long term effects of institutionalization (such a residential schools)
- The long-term effects of being in foster-care
- The overall maternal health and nutrition factors facing the mother
- Generational community and individual trauma resulting in the breakdown of families, loss of traditional ways of life, including spirituality and loss of traditional land bases (Boland, Burrill, Duwyn & Karp, 1998; Tait, 2001).

Barriers to Services Delivery and Treatment

In addition to the risk factors outlined above, previous research has found that pregnant women who are using alcohol and/or illicit drugs are most concerned about the possibility of losing custody of their unborn infant or the custody of other children, as seeking health care may lead to detection of substance use. A key barrier to engaging pregnant women in treatment is the mother's fear of losing custody of their children (Poole, 1999). Mothers who use substances identified shame as a barrier both in the process of disclosing substance use to child-protection workers in seeking support and treatment (Weaver, 2007). Barriers to accessing care for pregnant substance using women have been identified by other researchers (Poole & Isaac, 2001; Browne & Fiske, 2001; Sword, Niccols & Fan, 2004; Hume & Bradley, 2007; Vaillancourt & Keith, 2007) as including:

- Fear, shame, denial, embarrassment and/or guilt
- Isolation from family and support systems including geographic isolation
- Presence of domestic violence and control by an intimate partner
- Low or no income
- Inadequate housing or homelessness
- Feelings of self-loathing, hopelessness, and low self-esteem
- fear of forced treatment or criminal prosecution
- coexisting mental illness



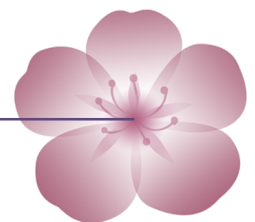
- Lack of or differential access to basic health care
- Lack of access to health care because of rural and remoteness locations
- Challenged by transportation costs
- Absence of child care
- Lack of integrated services
- Fear of losing their children to child welfare authorities
- Fear of being treated prejudicially
- Negative attitudes by health care providers and responses that stigmatizes women
- Traditionally there have been separate service delivery systems for prenatal care and substance abuse treatment rather than a collaborative approach that offers a continuum of care to meet women's complex needs
- Health care workers might lack not only the knowledge and skill to identify substance abuse in pregnant women, but also familiarity with available resources and therapeutic management
- workers in substance abuse treatment are unlikely to have the capacity to adequately address needs specific to pregnant women

For Aboriginal women the barriers to accessing addiction treatment can range from addiction programs not accepting pregnant women because of their 'medical' condition, to factors such as not having the proper health coverage status card, or band membership (Tait, 2000). Tait highlighted that,

... many addiction programs are residential programs which mean that women have to find alternative childcare if they have children, a task which creates its own set of problems, especially if the woman has experienced previous problems with child welfare services because of her drinking. Furthermore, most facilities have long waiting lists, with no provisions for pregnant women to be given entrance priority (Tait, 2001, p.101).

Social Determinants of Health

Whose knowledge matters and who has the power to label birth mothers as being responsible for medical diagnoses applied to children who show physical and/or neuro-developmental characteristics associated with FASD? That is the question posed by Schellenberg (2007) who critically reflected on how it is that we come to "know" mothers as being solely responsible for causing FASD disabilities instead of focusing on the inequitable social, environmental, and economic factors that lead women to drink? The single-minded focus on alcohol as the cause of FASD fails to account for other factors that may also contribute to neurodevelopmental problems. Birth defects, Schellenberg (2007) posits are "likely interrelated with multiple factors such as nutrients, genes, and enzymes" including the fact that the paternal alcoholism of fathers may also affect a fetus (p.109). She questions why it is that FASD occurs primarily among poverty-stricken women which fail to also take in account other common factors, such as smoking and poor diet which depart, from the medical approach to knowing what "causes" FASD. She further indicates that the medical diagnoses of FASD as "fact-based authoritative evidence provides a particular way of knowing women and their children" and that "this way of knowing obscures the experiences of "poverty, violence, abuse and other factors that contribute to women's poor health and to problematic substance use in the first place" (p.109). As it stands the current medical fact based



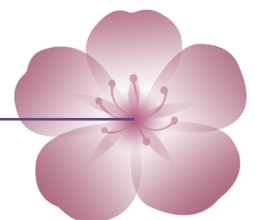
approach coupled with the act of assigning women individual responsible for social and structural inequalities that result in children with FASD is “socially and morally reprehensible” (p.109).

In support of Schellenberg’s premise, Marcellus and Kerns note that nature (i.e. the genetic or biological make-up) and nurture (i.e. the environment in which an individual lives and grows) are important influences that impact on women’s wellbeing and perinatal substance use. Alcohol and substance misuse is a complex issue, and women who misuse substances often struggle with multiple life challenges that include living in poverty, being homeless, having a mental illness, experiencing violence, trauma and or ill health (Marcellus and Kerns, 2007). The complexity of these issues required a broader framework for understanding the evidence on health outcomes particularly for women who misuse substances. In looking at the issue of FASD and in mother blaming, the social determinants of health need to be considered as one of the many compounding social and environmental factors that contribute to individual well being and perinatal substance use. Marcellus and Kerns define “social determinants of health” as the “socio-economic conditions that influence the health of individuals, communities and jurisdictions as a whole” (p.39). Social determinants of health are the economic and social conditions under which people live which determine their health. Virtually all major diseases are primarily determined by a network of interacting exposures that increase or decrease the risk for the disease. Health conditions are as a result of collective social, economic, and political forces (WHO, 2003). Social determinants of health have been recognized by several health organizations such as the Public Health Agency of Canada and the World Health Organization to greatly influence collective and personal well-being. People’s lifestyles and the conditions under which they live and work, strongly influences the health of people. The following determinants of health identified by Marcella and Kerns, that impact on health outcomes for women and children include:

- income and social status
- social support networks
- education
- working conditions
- physical environments
- biology and genetics
- personal health practices and coping skills
- access to health services
- gender and
- culture

Using a chart, Marcellus and Kerns identify the social determinant factors that apply in instances where there is perinatal substance use. These are briefly covered below:

- *Poverty*: Mothers who abuse drugs and alcohol often cope with financial and social difficulties. Life under poverty compromises mothers’ abilities to provide a consistent nurturing environment for their children.
- *Social Support Networks*: Impairments to social functioning are evident when there are substance use issues. Women dealing with substance abuse may also be coping with violence as well as a past history of physical, emotional, and sexual abuse. Partner violence may be higher in

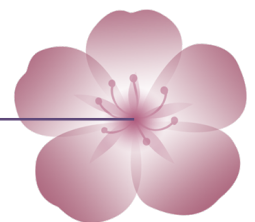


this group. Intergenerational effects from a lack of social supports also mean that children are apprehended and placed in foster care. Risks related to care include multiple moves as well as lack of consistent caregivers for children to attach to.

- *Education:* Women with substance use have lower educational achievement and frequently leave school early.
- *Working Conditions:* Women with addictions tend to be unemployed and/or underemployed. Women with lower educational attainment tend to be overrepresented in low paid jobs and among those receiving social assistance. They also tend to support younger children and have very little opportunity to advance to higher paid positions.
- *Physical environments:* Women with addictions often lack adequate housing in safe neighbourhoods.
- *Biology and Genetics:* There are biological and genetic differences among individuals in the absorption and metabolism of alcohol and drugs.
- *Personal Health Practices and Coping Skills:* Because of their addictions, many women have difficulty practicing health skills. This includes accessing health, safe housing and advocating for resources for themselves to enhance their health.
- *Health Services:* Women with addictions may not have a regular doctor and may fear disclosing their substance abuse to their doctor. They are overrepresented among those who use emergency care and fail to follow up on chronic health issues they may have.
- *Gender:* Women face socially constructed values and mores around the use of alcohol and drugs. Society tends to accept men as more likely to have addiction issues than women and consequently, treatment programs tend to be based on models that are more male-focused than female focused. Sex and gender are socially constructed but for women, differences in physiology and culture environments place women at great risk of substance use.
- *Culture:* Aboriginal women experience a disproportionate burden of health problems. Aboriginal people in particular are at a higher risk for substance use, particularly women during pregnancy (adapted from Marcella and Kerns, 2007, pp. 40-43).

While the research in this field is rapidly evolving and improving in quality, Marcella and Kerns note that the environmental context of women's lives and the social determinants of health impact on prenatal substance exposure play a much larger role than previously thought. It is important for policy developers, researchers and practitioners to stay abreast of the current research and critically interpret the material presented as it pertains to women and perinatal substance use.

The social determinants identified above collectively play a vexing role in the lives of women at risk of and/or dealing with substance abuse as substance-using women tend to have children apprehended by child welfare when there is evidence of substance use. Weaver (2007a) notes child welfare practice, standards, and discourse shape the lives of substance-using mothers. Harm, she remarks, is perpetuated against substance-using mothers at various social levels from social-assistance and child welfare offices, to family and criminal courtrooms, medical clinics, prisons and hospitals (p.76). More particularly the risk assessment models developed and used in the medical field pathologizes women who are dealing with substance problems and further, this approach tends to dominate the way in which child welfare policy and practice responds to and deals with substance-using mothers. In order to understand why this deficit based approach was utilized in British Columbia Weaver conducted two surveys (in 2002 and



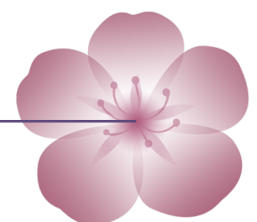
2003) and a qualitative study in 2003. The surveys focused on understanding worker knowledge about drug and alcohol addictions theories including the educational and availability of training needs for provincial child welfare workers in effectively working with substance-using mothers. The qualitative study focused on examining the relationship between provincial child protection workers and substance-using mothers and the response to a substance-focused risk assessment model used by the BC Ministry for Children and Family Development. These are discussed very briefly in the following six paragraphs.

Weaver notes that among the 40 social workers that participated in the first survey conducted in 2002 had a substantial caseload comprised of substance-using mothers (this was indicated as being at 69% according to the social workers' estimates). Despite this high caseload, Weaver found that child welfare workers self-rated knowledge of current interventions, approaches, and theory regarding problematic substance use was relatively poor. Further, she found it troubling that 30% of the workers in the survey knew nothing about the bio-psycho-social theory of addiction despite the caseworker's high caseload of women with substance using problems. This theory, Weaver indicates, can be viewed as a holistic concept of health that incorporates a variety of life areas in assessing and determining the needs of problematic substance users. In Manitoba, the bio-psycho-social theory is viewed as a complex interaction between various biological, psychological and social factors appear to contribute to the development of addiction problems (Addictions Foundation of Manitoba, 2002).

Workers in Weaver's first survey wanted to know how to facilitate and encourage change "without resorting to removal" as well as more comprehensive knowledge and understanding of street drugs and how drugs affect mothers and their ability to parent including the context of problematic substance use. Weaver indicates that social workers need to understand the power of addiction and the subculture that support it as this is often underestimated by social workers. Weavers identified that the adversarial framework inherent in the social worker-mother relationship that develops through child welfare avenues produces denial on the part of mothers because they do not want to disclose their substance using problems for fear of losing their children. Social workers also noted an inability to collaborate with alcohol and drug counsellors despite the fact that they shared the common goal of family preservation. Social workers complained that counsellors "appeared to advocate for their clients against the Ministry without all the information." The difficulties, Weaver indicates, lies in the fact that the child welfare discourse and approaches tend to contribute to a divisive practice that pits mothers against children. For instance, this puts "the counsellor and mother in one corner, and the child protection worker and child in the other" (p.78). This divisiveness could be alleviated she notes through more collaborative family-centred social work approaches.

The second survey conducted by Weaver in 2003 looked at the availability of curricula on substance misuse within social work programs in British Columbia. The findings from that survey indicates that substance-misuse and addiction training to students varied and that a major university offered no such courses at the undergraduate level. The training provided by the BC Ministry for Children and Family Development was also found to be scant and had not been offered since 1999 through its core and supplementary training to social workers.

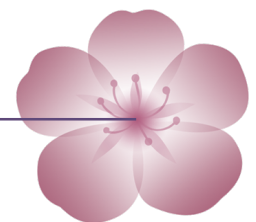
The qualitative study, conducted by Weaver in 2003 on the other hand, was small but produced some rich data about the nature of the relationship between substance-using mothers and child protection



workers. It was carried out with three child protection workers and among four former substance-using mothers who had previous involvement with the child protection system. Two focus groups were conducted individually among these two groups. Child protection workers experienced discord in working in a child welfare system that seemed unable to respond effectively, preventively or with compassion when dealing with substance-abusing mothers. Child protection workers expressed frustration with standards of training and practice that did not prepare them for dealing with substance-using mothers nor did their training prepare them for returning children or working collaboratively with mothers. More specifically the social workers noted problems with the time lines within the legislation. One child protection frustrated with the child protection system's response to mothers' recovery efforts, noted that "you can't fit a timeline on someone who's in recovery" (p.79). Fear governs the relationship between substance-using mothers and child protection workers. For workers, this fear is around their lack of knowledge about problematic substance use while for mothers, confrontation approaches tend to diminish any chance for an open relationship to develop. Mothers may not like what is written about them because they have no control over what is written and child protection workers indicated that they do not like being placed in an investigator type of role that prevented open relationships from developing. Child protection workers noted that "they felt distrusted and disliked playing 'private eye'" while mothers felt "afraid and ashamed, hide, deny and minimize the truth." Moreover it was found that the risk assessment models relied upon in the Ministry tended to separate and isolate the mother and her behaviour from her context. That is social workers, through the use of risk assessments (i.e. through the use of the *Risk Assessment Model for Child Protection in British Columbia*), produce a text that is wholly separate from the mother's lived experience and tend to ignore the stresses she deals with on a day to day basis and does not take into account the strengths in her relationships with her children (p.81).

In addition to the risk assessment model, workers must follow the Ministry's *Practice Guidelines for Assessing Parental Substance Use as a Risk Factor in Child Protection Cases* (the practice guidelines). This guideline notes that "the needs and interests of the substance-using parent are secondary to the well-being of the child" which Weaver notes is another divisive approach to families. In particular Weaver notes that it contributes to the absence of positive feelings by children about their parents, which can become a barrier for working successfully with young people. Weaver also identified that the practice guidelines tend to omit the consideration of the impact of poverty on the family and the lack of access to resources and services to assist the family. Weaves observed that it is important to remember that "substance use in itself does not constitute a child protection concern" (p.81). Furthermore the guidelines do not encourage collaborative work with parents who have substance abusing issues. Instead, the practice guidelines tend to collaborate with addictions counsellor and not the parent.

Another problematic approach that Weaver found in her qualitative study in the relationship between substance-using mothers and child protection workers was in *Parent Substance-Use Questionnaire* that social workers have to complete when working with substance-using mothers. She suggests that the form does not account for the realities of the parent's lived experience and that it is not "user friendly" in that it classifies parents, quantifies their drug and alcohol use and excludes important parts of their lives. Weaver says this builds a case against, rather than helps parents. The questions as they are asked (i.e. *describe your use of alcohol, what substances have you used in the past, how long have you been using, etc.*) don't allow for honest answers and it is unlikely any substance user or parent would answer them honestly. Asking these types of questions also don't contribute to the development of a positive



relationship between parents and social workers as they are questions designed to elicit information that could be used against parents in family court (Weaver, 2007a, p.82).

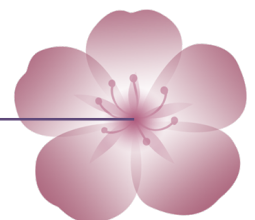
Weaver's research highlighted that what *did* work in the relationships between substance-using mothers and child protections were elements that factored in the humanness of mothers and for workers to be non-judgmental, including:

- Having faith in the parent
- Not looking down on the parent
- Providing choices to parents (i.e. connecting mothers with foster mothers who in turn make the substance-using mother welcomed)
- Workers acting more human with feeling towards substance-abusing mothers, more particularly, displaying empathy especially when mothers are scared
- Willingness to work with parents and not against parents or with the intention of removing children
- Ensuring that workers are non-judgmental in their approaches (adapted from Weaver, 2007a, pp.84).

Weaver points out that there are more effective ways of working with substance-using mothers. She suggests that government and child welfare systems should turn their gaze toward exercising a more strength-based social-work practice and focus when working with vulnerable, stigmatized populations. Weaver indicates that child protection has often worked in direct opposition of its legislation and in the result created unintended suffering, especially in considering that social workers enter the profession with a commitment to model compassionate, helpful and creative approaches to working with families in crisis. In particular, the systems need to “think outside of the box” and review its outdated values, beliefs and expectations with respect to substance abusing parents. Weaver advocates adopting a strengths-based approach that cultivates options and one of the ways that this can be done is through a shared-parenting model that was highlighted in her qualitative study. Shared-parenting was described by some of the mothers and workers as being a situation where there is “supportive teaching relationships between birth parents and foster parents that are facilitated by child protection workers” (p. 89). Weaver explains that the shared-parenting model meets the needs of all family members, facilitates healing and preserves birth family connections. In particular she notes that a shared-parenting approach recognizes:

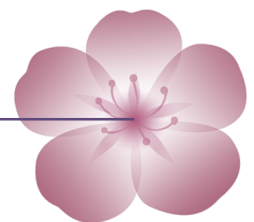
... that the connection between parents and their children is the single most powerful relationship upon which to build or preserve families, shared parenting emphasizes establishing an alliance with parents to protect their children rather than just an alliance to protect them from their parents.

By taking such an approach Weaver posits that a shared parenting approach to practice provides a unique opportunity to both social workers and foster parents to provide nurturing to birth parents and children alike but that training and support for supervisors, managers, line-protection workers and foster parents is required to facilitate this change. Such an approach offers a “modern approach” to child protection.



Weaver (2007b) later noted that child welfare workers are in a key position to be able to reduce harm and strengthen mothers affected by problematic substance use. She indicates that child welfare workers are well positioned to reduce the shame that often presents a barrier to women accessing treatment and recovery. She indicates that if social workers are given training that guides them towards a helpful approach – and policies and procedures support that approach – social workers can help mothers who use substances, rather than perpetuate the systemic harms associated with risk-based and judgmental methods (p.282). This training approach was described in her publication *Shame Reduction: A model for training child welfare workers on best practices with mothers who use substances* (Weaver, 2007b). This training course was called “Best Practice with Substance-Using Mothers: Training for Child Welfare Workers”, was developed and delivered through the School of Social Work and Family Studies at the University of British Columbia by Weaver. Weaver conducted the course with the active participation of mothers who had used substances. Through the course, students’ became aware of the unrealistic expectations placed on mothers who had used substances as well as came away from the course with a greater understanding of the realities of these mothers’ lives. The course focused four components involving:

- *Providing child-protection workers/students with information about street drugs and their effects:* The purpose of providing this information is not to make workers better at “policing” substance use but rather to demystify it and to reduce both workers’ fear of people who use substances and the behaviours that accompany this fear (e.g. confrontations, investigative rather than collaborative approaches, judging, “building a case” against a mother).
- *Encouraging workers to examine their values and beliefs about working with mothers who use substances:* This phase of the training involved experiential learning with respect to power and control issues; participants take part in two life skills exercises that allow participants to examine their attitudes toward control and collaboration. By reviewing their ethics and their roles, workers in the training program begin to look at their own attitudes and move toward a practice that involves listening non-judgmentally. Workers can then help mothers disclose problematic substance use, support them and offer to meet their needs for accessing treatment and reducing barriers to access.
- *Reviewing models for and theories on working with people with substance use problems:* Intervention models and theories for working with people with substance use problems are summarized. Motivational interviewing and harm reduction theory is explored with discussion on how workers can apply these concepts.
- *Inviting workers to collaborate with mothers to focus on their strengths and needs:* The last part of the training involves workers conducting interviews using the “Family Plan of Care and the Parental Capacity Strengths Assessment” documents which Weaver developed to help guide the discussion between workers and mothers in a way that would help workers focus on mothers’ strengths and needs and collaborative with them in planning. Workers are encouraged to be real with mothers rather than maintaining an emotional distance. Weaver notes that “when workers focus on strengths, they are no longer prone to depicting the mother in a negative light to their children, foster parents, family members or the mothers’ significant other; instead, she states, they can help strengthen the natural support network potentially available to mothers.



In closing Weaver states that when social workers and mothers are able to talk with each other their conversation can offer significant learning about how to achieve more positive, collaborative and supportive child welfare practice.

Alternative Approaches and Examples of Wise Practices in Working With Pregnant Women and Parenting Mothers who are Substance Using

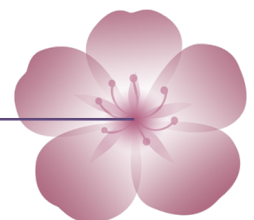
Nancy Young writes compellingly on the importance and benefits to collaboration between the child welfare and alcohol and drug agency fields, particularly in supporting strengths-based assessment and in broadening the lens through which alcohol and other drug problems are viewed (Young, Garner, & Dennis, 1999). It has been recognized that women who become pregnant and who are struggling with addiction issues seldom seek treatment services which raises the risk levels to both pregnant women and their developing fetuses (Tait, 2001). Several programs have been developed across the provinces to address the needs of these women in a way that reduces harm and is woman centered. The samples that follow were drawn extensively from the book *Highs & Lows: Canadian Perspectives on Women and Substance Use*, edited by Poole and Greaves (2007), two leading researchers who have done widespread research on women and substance abuse within Canada. Women's and girls' substance use is now recognized as an important health, economic and social issue in Canada. However, Poole and Greaves note that most books about alcohol and other drug use do not address the unique needs and circumstances of this population. *Highs & Lows* was coordinated to address this short coming and draws on the latest theory and research to offer strategies for improving practice and developing policy to support women with substance use problems. This unique book includes contributions from nearly 100 experts on women's substance use, including psychiatrists, psychologists, social workers, clinical therapists, health promoters, academics, alternative health care providers, women's health advocates — and women who have personally been affected by substance use. The book includes in-depth chapters on:

- The interconnection of trauma, mental health and substance use problems for women
- Pregnancy, mothering and substance use
- Innovative treatment, harm reduction and prevention programs designed with women's needs in mind
- Challenges and opportunities for improved research, treatment and policy development.
- Snapshots of the latest in women-centred research, treatment and policy innovations
- Statistics on women's substance use in Canada
- Women's personal narratives of their experiences of substance use problems.

Breaking the Cycle Program - Toronto

One particular program highlighted by Leslie (2007a; 2007b) is that developed by seven participating organizations in Toronto³. "Breaking The Cycle" or BTC was developed to provide comprehensive,

³ The efforts of the seven organizations include: The Canadian Mothercraft Society, the Jean Tweed Centre, the Motherisk program at the Hospital for Sick Children, the Children's Aid Society of Toronto, the Catholic Children's Aid Society of Toronto, Toronto Public Health and St. Joseph's Health Centre. Funding for the program is provided by the Public Health Agency of Canada through two of its programs: The Community Action Program for Children and the Canada Prenatal Nutrition Program (Leslie, 2007, p.239).



relationship-based service delivery using a range of integrated maternal-child services available through a single access point, with both home visitations and outreach components. The BTC program brought previously disconnected services together to create an environment which works in facilitating and engaging pregnant women who use substances with services to ensure optimal outcomes for both the mother and her child. The BTC program was launched in 1995 with the belief that services should be coordinated so that agencies adapt to families rather than having families adapt to agencies. The goal of the BTC program includes addressing existing service system problems the pregnant substance-using women have faced, such as:

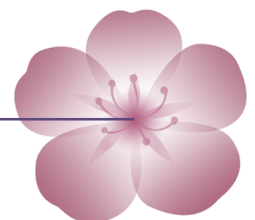
- Fragmentation of services for pregnant women or mothers who use substances and for their young children
- Multiple intake experiences
- Poor coordination of services, especially between the adult-treatment sector and the children's-service sector
- Lack of consistency
- Scattering of service access across multiple locations

The types of services provided to pregnant and/or parenting women who use substances and the types of services provided to their children through the BTC include the following:

- Individual and group addiction treatment
- Parenting programs
- Child care
- Child developmental services (including screening, assessment and intervention)
- Health services (including a pediatric clinic and addiction medicine)
- Mental health counselling
- Case management and service coordination
- Parent-infant counselling
- Home visitation
- Pregnancy outreach
- Support around instrumental needs (including food, clothing and transportation) (Leslie, 2007, p. 240-241).

Leslie notes that based on various evaluations, the BTC has been deemed a success (Health Canada, 2003; McMurtie et al, 1999; Motz et al, 2006; Pepler et al, 2002; Roberts & Nanson, 2000; UN Office on Drugs and Crime, 2004). Leslie further notes that mothers echo this perspective as evidenced in the following mother's comments:

Addicts sometimes have a hard time getting their act together and controlling their lives. BTC is a one-stop shop. A lot of places will help you with one thing, but you have to go across town to get something else you need. Here, they deal with you, your children, parenting and emotions all under one roof (as cited by Leslie, 2007, p. 241).



Several key elements that mothers in the program identified as contributing to this success included: acceptance, empathetic understanding, honour, respect and empowerment, caring, love and hope. In particular, a number of participants identified respect, and feeling respected, as a meaningful component of the growth-promoting relationships they were able to experience through the BTC Pregnancy Outreach Program. Leslie (2007) noted that this was reflected in comments such as that made by the following women:

The message I got from the BTC the struck me and helped me through? The main message was that they cared about me and my child and that, no matter what, they would help me and ... they seemed to like me even through I didn't like myself. They kinda loved me back to life again. And just that I could do it, that I ... was able and that, you know, even though I had kind of given up on myself, that there was still hope, and that it's possible and that I could do it. Basically that is what the main message that they gave me. They gave me hope.

BTC expanded its program in 1999 to include outreach services to engage homeless, pregnant women using substances to ensure they too were receiving and had access to health, treatment and social-support services. Hicks (1997) found that homeless women who are pregnant and using substances have greater barriers to accessing health and treatment services than other women who used substances and were not homeless. The BTC outreach program facilitates the following:

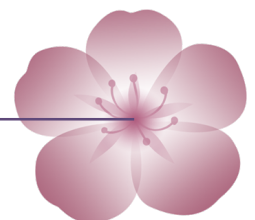
- Engagement with women earlier in pregnancy to improve maternal, fetal and child health outcomes
- Development of service relationships among street-based organizations having contact with homeless women who use substances

Leslie identified a satellite groups that operates through BTC in addition to outreach for homeless substance using women. This satellite group is a support group for women in the outreach program. This group combines relapse prevention, prenatal health and psychosocial/attachment goals. It is offered weekly through a partnership with the Toronto Centre for Substance Use in Pregnancy at the St. Joseph's Health Centre and the Women's Own Withdrawal Management Centre.

A subsequent evaluation of the BTC program proved it a successful in reaching homeless pregnant women who use stances. In addition BTC helped decrease women's isolation from service-providers and engaged women early in their pregnancies that resulted in a more positive maternal and child health outcome for these women. Leslie notes that it is only through the process of engaging women who are pregnant and using substances that they have come to understand the reality of their lives, including the context within which they use substances.

Sheway – Downtown Eastside, Vancouver

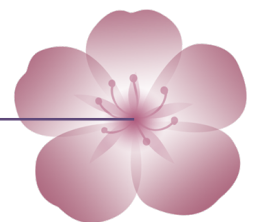
Another woman-centred approach to engaging women who are pregnant and/or parenting with substance use issues is a project found in the downtown eastside of Vancouver. The program "Sheway" provides holistic services to pregnant women and support to mothers and families with substance use problems until their children are 18 months old. Sheway started in 1993 in response to high levels of substance use by pregnant and parenting women including the recognition that high rates of children



were being born with low birth weights at infancy. In addition they noted that high numbers of children were apprehended by child protection authorities (Poole, 2007). Sheway takes a women-centred; harm-reduction based and culturally focused approach to providing services. This approach was found to be highly effective and successful when the program was subsequently evaluated (Poole, 2000). Poole (2007) succinctly highlighted many of the reasons why the Sheway program was successful:

- By engaging women who use substances and are at high risk in prenatal and postnatal care on a range of health and social issues. At intake, 30 percent of women had no medical or prenatal care, and by the time of their deliveries 91 percent were connected to a physician or midwife;
- Supporting women as they improve their nutritional status. Of the women accessing services, 79 percent had nutritional concern at intake, whereas only four per cent had nutritional concerns at six months postnatal. Nutritional concerns were defined as fewer than three meals a day, lack of money to buy adequate food, lack of knowledge of nutrition and food resources (i.e. food banks) or lack of kitchen facilities. Women who use Sheway's services are provided prenatal vitamins, hot lunches and information about food banks and community kitchens, as well as nutritional counselling – all of which may have contributed to improvements in nutritional status.
- Supporting women as they improve their housing. At intake, Poole notes that 27 per cent of the women had no fixed address, and 65 per cent in total had housing concerns. By six months after childbirth, only six percent of them had any housing concerns. Housing concerns were defined as no housing or housing of inadequate size; in a poor location; with overcrowding problems; or with safety, health or structural problems.
- Increasing the number of children with healthy birth weights. 86 percent of the babies whose mothers accessed care at Sheway were known to have a healthy birth weight (over 2,500 grams).
- Helping women retain custody of their children. Over half (58 percent) of mothers who used Sheway's services were able to retain custody of their children (22 percent had no involvement by the Ministry for Children and Families, and 36 percent had ministry involvement for support only). The remaining 42 percent of mothers did have their children apprehended; in these cases 37 percent were later returned to the care of the birth mother or her immediate family (Poole, 2007, pp.247-248).

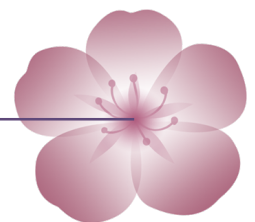
Payne (2007) describes another philosophy of care that emerged in British Columbia around the issue of pregnant women using substances called the "Fir Square Combined Care Unit" within the BC Women's Hospital and Health Centre in Vancouver (hereafter "Fir Square"). Their approach to working with pregnant women who are using substances is one that is a women-centred with a harm reduction orientation. Since its inception in 2003 Payne (2007) indicates that over 450 women have benefitted from the services offered at Fir Square. The Fir Square program was developed to assist women who were involved in the Sheway program as a way to focus on offering medical stabilization and withdrawal management for pregnant women with substance use problems. The women coming for care were dealing with poverty, hunger, unstable living conditions, low levels of social support, and histories of violence, exploitation and often of having their children removed by child welfare authorities. Other than Fir Square, there is no other place within the province of British Columbia where pregnant women can access opioid withdrawal management and/or methadone services. Payne notes that prior to these two programs there was no other way of dealing with pregnant women with substance abuse problems

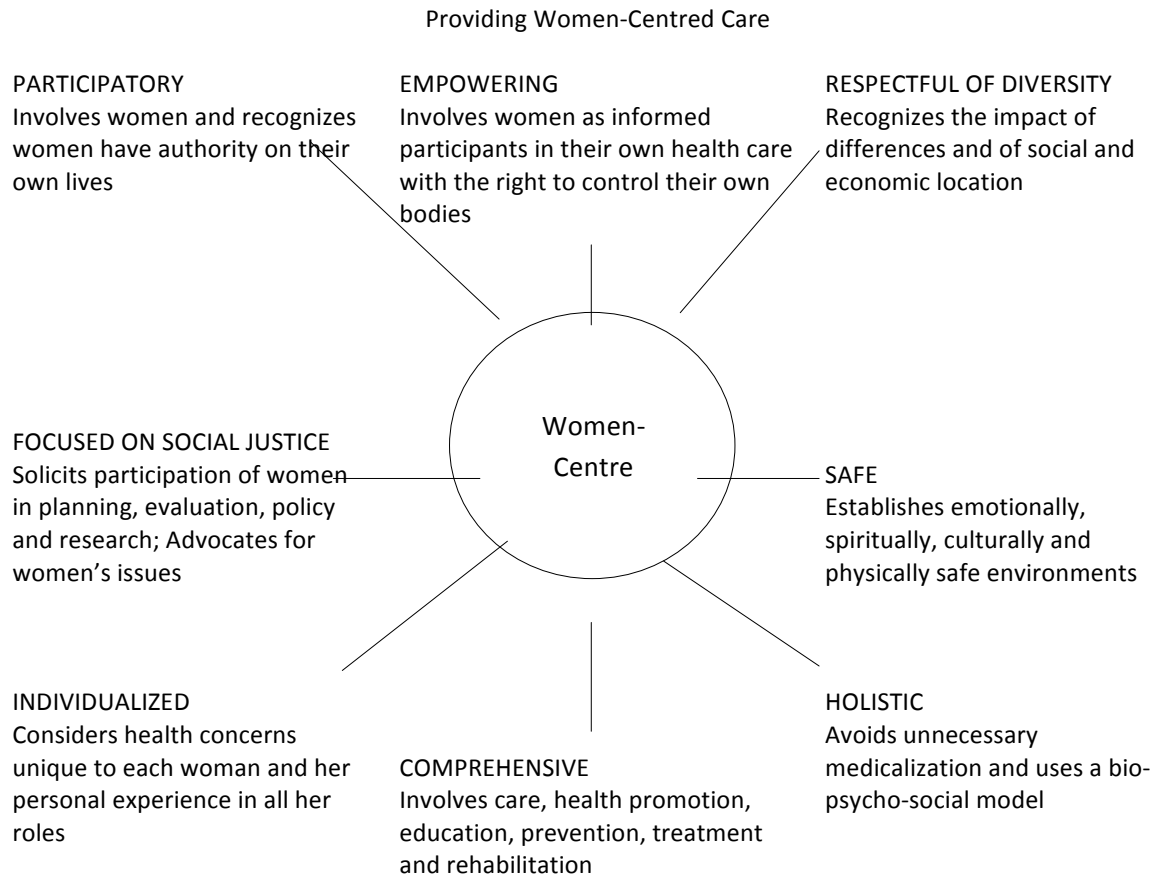


other than to believe they were incapable of mothering at which time when they delivered their babies would then be apprehended.

Abstinence from all drugs and/or alcohol was thought to be the only goal for mothers. In the past, many pregnant substance-using women as a result avoided medical care until the last moment before giving birth. This was because they received hostile responses and because earlier medical responses tended to focus more on the health outcomes of the baby to the exclusion of the mother (Boyd, 1999). This response, notes Payne (2007) “usually resulted in the women giving up hope for their own recovery, health and parenting abilities” which led many women back to the streets and their baby consequently apprehended by child welfare authorities (p.250). As noted earlier, Poole and Isaac (2001) demonstrated that this outdated perspective only served as a barrier to care for women in these circumstances. Feelings of shame, guilt and fear of being judged and/or having their children taken away only served to prevent pregnant women with substance-use issues from accessing care. At Fir Square women struggling with problematic substance use can come anytime knowing that whatever they do, they will always receive care; that care is not entirely dependent on being abstinent but rather one that is based on reducing harm.

Payne (2007) provides an in-depth description of how Fir Square applies a women-centred and a harm reduction orientated approach to working with pregnant women with substance-use problems. Fir Square, through their services, help to minimize the health risk to mothers and their babies. Their services allow for empowerment of women and acknowledge that women must be at the helm of decision making over their own care and suited to her individual needs as well as making these changes at their own pace. The philosophy of care at the centre of Fir Square approach is visualized in the diagram below:

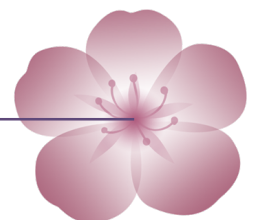




Source: Cited in Payne (2007) at p.251, © British Columbia Centre of Excellence for Women's Health, 2001.

This approach incorporates a number of principles and approaches that were developed collaboratively between clinicians and researchers working with women in a range of programs and projects across the BC Women's Hospital Centre. Comprehensive care is provided by a team of physicians (in family practice, obstetrics and pediatrics), nurses, a social worker, a substance use counsellor, an infant development worker, a nutritionist, and a senior practice leader, a unit clerk and housekeeping staff. The unit has 11 beds and is staffed 24 hours a day by four nurses. In addition a family practice physician with expertise in caring for women with problematic substance use supports the team. The team is supplemented by a recreation therapist and a chaplain. As many of the women accessing Fir Square services are First Nations, a First Nations advocate visits every day (Payne, 2007). Women can self-refer to Fir Square or they can just turn up. If they lose their identification or do not have health coverage or an address, they are not turned away. They are seen by a physician and a social worker regardless of lack of identification; prove of residence and/or health coverage. In this way, Payne says, the social worker can start working on obtaining the medical coverage as well as financial aid and helps to connect the pregnant women with linkages for when she comes in to deliver her child.

Critical to the services of Fir Square is the work of the social worker who acts as a case manager and liaison between the Ministry for Children and Family Development and the women. The social worker is



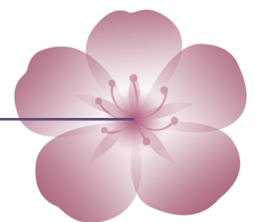
instrumental in helping the women find housing and works with the entire time to plan the women's discharge from the hospital. Women are supported in their mother by "walking beside them" in their journey during their stay at the hospital. Women normally stay an average of 14 days but may stay on longer as staff does not find it ethical to turn a woman out just as they are beginning to journey towards health and parenting. Staff do not want to see a new mother's baby removed because she does not have a safe place to live or no healthy supports in the community. Fir Square's mandate, Payne notes, is to work with the Ministry but they will only engage the help of the Ministry if they have the patient's consent to do so. Their philosophy is that women have to be medically stabilized but also able to be mothers and care for their babies before they can be discharged. Having women stay 14 days or longer is often instrumental in ensuring that mothers and their children return to the community together as a intact family unit. In closing Payne notes there is still much to learn from applying a harm reduction and woman-centred approach to caring and she notes that follow up research will be conducted with women three months after they have left the hospital to see if they have been able to maintain care of their infants and whether they were able to get connected to the ongoing supports they needed.

Pathways to Healthy Families - Toronto

In Toronto, an interconnecting service network was created called "Pathways to Healthy Families." The goal of this program, funded through the Ontario Early Years Addictions Initiative, is to reach pregnant women and mothers with young children who are substance using and experiencing barriers to care. This program came into existence when the Jean Tweed Centre conducted a needs assessment and community consultation process in Toronto with service providers to explore a collaborative response to the Early Years Addictions Initiative. Those that participated included representatives from child welfare, education, mental health, public health, addictions, housing and children's services. These stakeholders⁴ "all agreed on the urgent need to build capacity within and across systems to better identify and service women who are pregnant and/or mothering young children (up to six years old) and who use substances" (Hume & Bradley, 2007, p. 258). The stakeholders proposed moving outside the boundaries of traditional on-site programming to a broader system of response defined by population, geography and service type, where capacity would be built through training and education, coordination and case management, counselling and support.

The Pathways to Healthy Families service approach is one that centres on the principles of harm reduction, active care and advocacy. The traumatic life experience of the women it serves is acknowledged along with the complicated choices that women must make. With a focus on healthy child development, efforts are made to ensure that women receive the information and support they need to make informed, healthy decisions. Counsellors work quickly to connect women with local resources, advocate on their behalf and link them with parenting and medical care (Hume & Bradley, 2007, p.259).

⁴ This stakeholders were identified by Hume and Bradley (2007) as being: The Jean Tweed Centre, Pathways to Healthy Families (lead agency); Rosalie Hall; Rexdale Community Health Centre; Massey Centre for Women; Native Child and Family Services of Toronto; and Lawrence Heights Community Health Centre (p. 262).



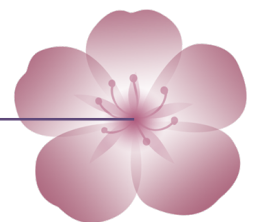
The Pathways to Healthy Families approach includes a Child Development Centre that services the needs of mothers who use substances, as well as those the needs of their children. The fundamental objective of the Pathways model includes both mothers and children as clients. There is a child development centre available which offers enhanced child care services that meet the particular needs of mothers using Pathways. Early childhood education consultants are cross-training in counselling people with substance use problems and offer many related and integrated supports. Offering child development services was seen as essential, not only as a support to mothers engaged in treatment, but as part of a support to mothers engaging in treatment, but as part of a holistic approach that pays special attention to parenting skills and to infant and child development and attachment issues, in addition to substance use issues (Hume & Bradley, 2007, p. 259).

The impact of the Pathways program has been seen as positive in that a request for similar services is growing across Toronto. Overall, Hume and Bradley (2007), note that women are engaging earlier in their pregnancies, fewer babies are being born prematurely and there are improvements in the birth weights of infants. It has also been noted that many of the women “are for the first time voluntarily engaging in plans of care with child welfare services” giving women opportunities to play a meaningful role in their children’s future” (p.260). Hume and Bradley note too that there are challenges to overcome. They identified these challenges as being:

- *Partnerships* – ensuring that partnerships are nurtured and maintained. There is recognition that participation, ongoing dialogue, respect and flexibility are necessary ingredients to keeping these partnerships dynamic, alive and healthy;
- *Capacity* – demand is growing and caseloads are high; this could result in the program slowing down which leaves the program vulnerable in meeting its goals. The Team needs to be creative in its efforts to balance direct service, case management and community development efforts.
- *Education* – more information and training is needed in substance use and mothering to be offered to multiple sectors in the community at earlier points and should be offered at universities and colleges that teach medicine, nursing, social work, justice, child development and early childhood education.
- *Policy* – an integrated collaborative approach requires leadership, service dollars as well as funding and politicians educated about the importance about continuing to develop integrated service delivery as well as policies that support women with substance use problems in and through their healing and mothering (adapted from Hume & Bradley, 2007, p. 261-262).

FNIHB’s FASD Mentoring Program - Manitoba

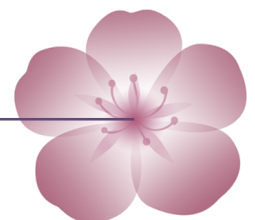
In Manitoba a FASD mentoring program, similar to the Stop FAS program by the Parent-Child Assistance (PCA) program developed by the School of Medicine in Seattle Washington was created. Women misusing, or at high risk thereof, are targeted for participation with the end goal of the program being the prevention of FASD or minimizing the severity of the disorder. It is a home visitation model implemented by paraprofessional mentors. The hallmarks of this three year home visitation model, implemented by well trained and closely supervised paraprofessional mentors (who have caseloads that never exceed 15 active client families per mentor), include:



- Mentors never giving up on a woman; women are never asked to leave the program because of relapse or setbacks.
- Mentors develop a network of relationships with everyone involved in a woman's life and provide advocacy for other family members as needed.
- The program continues to advocate for both mother and target child, as appropriate, regardless of custody issues.
- Mentors connect a woman's service providers with each other and facilitate development of an effective plan; services may include Child and Family Services, probation services, alcohol/drug treatment, health services, etc.
- The program links women with the best available community services, and identifies and actively resolves existing barriers. Although the mentor's role is intensive, it is not intended to provide the 'direct' services needed.
- Women identify and evaluate personal goals every four months, which mentors coordinate with program goals.
- Weekly supervision with each mentor and clinical supervisor is essential.
- Weekly staff meetings, including case reviews with the team are essential to help mentors learn from the progress of each other's clients, and to provide a venue for ongoing program training.
- Ongoing program evaluation generates information used by the program to examine outcomes and to enhance the work of mentoring (p.3).

An evaluation of three sites piloting the Stop FAS initiative in Manitoba by Umlah & Grant (2003) suggests that the program appeared effective in reducing the number of children born with FASD but there was also a need to evaluate the program specifically within a First Nations context. The Health Canada version of the mentoring program is offered in over 40 First Nations communities across Canada with some sites operating as long as three years. The overall program objectives are described by Health Canada (2008) are to: "Prevent Fetal Alcohol Syndrome Disorder (FASD) births through one on one advocacy for women at risk of drinking during pregnancy."

Alcoholism and drug abuse were at one time viewed primarily as "men's diseases." It has only in the past decade or so that there has been increasing attention paid to women's substance use and abuse (Poole, Horne, Greaves, Chovanec & Watkins, 2004). Although women drink less than men, the number of women who do drink is significant. Substance use in pregnancy is a major public health problem. It can have profound effects on pregnancy outcomes, and childhood health and development. Additionally, women who use substances have their own health-related issues. Although intervention is important, women in their child bearing ages who have substance misuse problems often have difficulty using and accessing traditional systems of care (Sword, Niccols & Fan, 2004). Women centered programs that utilize harm reduction strategies and techniques, such as those illustrated in this review, are showing promising results that will assist in reducing and preventing FASD.



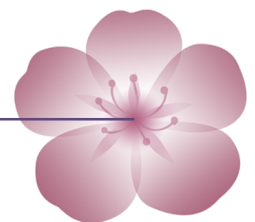
Section 5 – FASD Affected Youth Transitioning Out of Child Welfare Systems and Youth in Care with FASD Involved with the Criminal Justice System

Overview:

- Tremendous amount of literature that examines the issue of transitioning out of care for children in the child welfare systems across Canada but very few resources that focus on the transitioning issues for youth with FASD in either the Canadian or US literature;
- Research on youth with disabilities aging out of care yielded few resources specific to the Canadian context but plenty of research and government documents exist in the American context;
- Three provinces within Canada have looked at transitioning issues for youth with FASD specifically: British Columbia, Alberta and Manitoba.
- Idea of a “second brain” referred to in the literature - Over 80% of people with FASD are unable to function well enough to maintain employment or live on their own in the absence of supports;
- Key area that impacts on successful journey towards independence is the connection to understanding the development of “secondary disabilities” for youth with FASD.
- The presence of secondary disabilities also explains why there are higher levels of individuals with FASD involved in the criminal justice system in both the juvenile and adult streams.
- Secondary disabilities are instances where young people with FASD experience behavioural and mental health problems in adverse environments and when their needs to deal with the primary disabilities related to FASD are not met. Secondary disabilities are identified as being:
 - Mental health problems;
 - Disrupted school experiences – (suspensions, expelled or dropped out);
 - Trouble with the law;
 - Confinement (including inpatient treatment for mental health or drug/alcohol problems or incarceration for a crime);
 - Inappropriate sexual behaviour (exploitation);
 - Victimization;
 - Alcohol and drug use problems;
 - Needing dependent living situations;
 - Problems with employment; and
 - Problems with parenting.

Sample of search terms used:

- Youth with FASD leaving care
- Youth with FASD transitioning out of the child welfare system
- Adolescents with FASD leaving care
- Youth with FASD involved with the criminal justice system
- Youth with FASD and crime
- Youth with alcohol related disabilities and the justice system
- Youth with FASD leaving government care
- Youth with FASD transitioning to adulthood
- Youth with FASD and adult independence
- FASD affected youth and the criminal justice system
- FASD affected youth and corrections
- Delivery of services to youth offenders with FAS/FAE
- Correctional services and FASD affected youth



- The literature also discusses factors where the adverse impacts of secondary disabilities can be alleviated (for instance, some of these include being diagnosed early; living in a stable environment, not experience violence in the home, long term stability).
- Understanding this issue lead to the amalgamation of these two areas as the existence of secondary disabilities impacts on the ability of youth with FASD to transition to adulthood in a healthy way.
- The research that exists focuses on the high incarceration rates of Métis and other Aboriginal people in the justice system in both the adult and juvenile corrections streams.

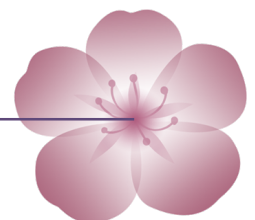
Transitioning from Care

As mentioned previously children born with fetal alcohol spectrum disorder tend to end up in foster care. Research conducted by Fuchs et al (2007) say children with the disorder are generally taken from their families at a younger age and are more likely to spend the remainder of their youth in care than other foster kids. The ability of young people with FASD to achieve maximum independence and live full lives once they leave foster care is a major concern for families and child welfare agencies responsible for their care while they are still under the age of majority. Youth with FASD have more difficulty than other youth transitioning to adulthood, independent living and adult support systems (2008). A scan of research focusing specifically on the experience of young persons with FASD transitioning from government care to adult independence yielded very few Canadian resources on topic with the exception of one report produced in the Province of British Columbia and another recently published from Manitoba through the Centre of Excellence for Child Welfare.

The concern for the challenges facing youth with FASD as they transition from care to adulthood was the focus of a 2006 special report entitled *A Bridge to Adulthood: Maximizing the Independence of Youth in Care with Fetal Alcohol Spectrum Disorder* released by the Province of British Columbia through the Child and Youth Officer, Jane Morley. The report is specifically about youth in government care who have Fetal Alcohol Spectrum Disorder and their need for assistance to help navigate adult service systems that may be ill-equipped to deal with their unique needs when they reach the legal age of 19 years. The report identified that youth with FASD do better when in a structured home environment and when connected to adults who can advocate on their behalf. Unfortunately, supports beyond the age of majority are not necessarily easy to come by as individuals with FASD don't fit into any particular category of program within the adult stream of available resources and programs offered by the Community Living BC⁵ department.

The report looked at six youth in care with confirmed or suspected FASD focusing primarily on the things that they had in common: being in government care, living in Vancouver and within two years of their 19th birthday at which time they would be expected to live independently. These young people were characterized as having significant difficulty functioning at school or at home or in their community. None of the young people were street-involved although it was noted that some had brushes with the

⁵ **Community Living BC (CLBC)** delivers support and services to people with developmental disabilities, children with special needs and their families in British Columbia. CLBC can help families create individual support plans, ensures health and safety standards are kept up when children, youth, adults live away from their family. CLBC helps individuals and families get connected to their community and put paid supports in place when needed. It is the only branch of social services where housing supports for adults with disabilities can be obtained.



law and some were already dealing with substance abuse issues. Because of their disabilities, the six youth highlighted in this report were considered to be at high risk for poverty, homelessness, involvement with the justice system, and other poor outcomes.

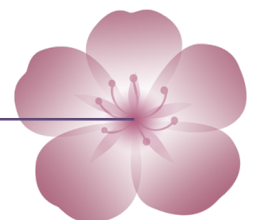
Profiles of the six youth in care were generated through interviews, questionnaires, and information collected from their caregivers, social workers and the youth themselves. A summary of the types of assistance they would need upon aging out of the child welfare system as created. The profiles were taken through a simulated review with service gatekeepers to determine what types of assistance these young people would qualify for upon turning 19 years of age. The types of supports youth with FASD would need included the following:

- Supported living services (part-time or full-time caregivers, and supported housing);
- Life skills and employment training and assistance;
- Financial assistance;
- Mental health and addiction services;
- Planning and case management services.

The simulation revealed that the adult services system would not offer most of these supports and further, that these services are not readily accessible by youth with FASD. Despite lower levels of adaptive functioning, the young people profiled in this report were characterized as having higher IQs in comparison to the individuals with disabilities who normally are eligible for supported living services offered through the Provincial Department of Community Living. The need for ongoing assistance was also noted in instances where they are eligible for disability benefits for instance from the Ministry of Employment and Income Assistance. The process of applying for and maintaining these disability benefits would not be possible without ongoing assistance. The report also went on to note that BC Housing provides subsidized housing for people with disabilities but there is both a long waiting list and very limited options for single people. Furthermore, none of the profiled youth with FASD had mental health diagnoses that would make them eligible for mental health services. The other noted barrier was in the need for addiction treatment. While the youth with FASD might be able to access these programs, it was acknowledged that cognitive approaches likely wouldn't work because of the youths' cognitive impairments.

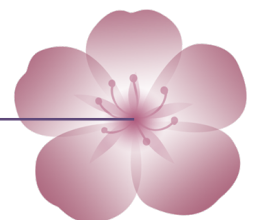
In concluding the report, six recommendations directed at the BC provincial government flowed from the report and they are reproduced from the Executive Summary of the report:

1. Invest in the development of a tool designed to assist the functional capacities and limitations of individuals requiring government services as an aid to designing appropriate services, and use this functional assessment tool to assist in planning for youth in care with FASD as they transition to adulthood;
2. Expand the eligible requirements of Community Living BC by recognizing low adaptive functioning as and equally important indicator of the need for lifelong community living services;
3. Develop a cross-ministry plan for youth transitioning to the adult service system, involving in the plan the Ministry of Children and Family Development, the Ministry of Employment and Income



Assistance, the Ministry of Health, the regional health authorities, and Community Living BC, and including with the plan:

- Identification of services needed by youth in transition;
 - A clear definition of the mandates of each agency to provide those services;
 - A strategy to fill any gaps identified;
 - Strategies to be implemented within the appropriate ministry or agency to make the services offered more responsive to the needs of vulnerable youth, particular those with FASD and other similar functional disabilities.
4. Provide funding through the appropriate ministry for focused education and training of professionals working with youth with FASD about the implications of this disability for service delivery and their practice.
 5. Revitalize the transition planning required by the Ministry of Children and Family Development's service standards, by initially targeting youth in care with FASD or suspected FASD, ensuring that for each youth in a planning process in place that:
 - Meaningfully engages the youth;
 - Includes adults who are significant in the youth's life in order to encourage the development of a network of support for the youth that will continue past age 19;
 - Incorporates a strength-based, culturally appropriate approach, and;
 - Is informed by:
 - A functional assessment and analysis, based on the use of an appropriate tool and information from those who best know the youth's functioning;
 - A diagnostic assessment;
 - A social mapping of existing and potential informal adult and community supports;
 - If the youth is Aboriginal, a full understanding of the youth's cultural context.
 6. Acknowledge the ongoing obligations of government to support youth for whom the government has been guardian, and develop a 19-23 transition-to-adulthood case management program, to be administered by the Ministry of Children and Family Development. Begin by targeting youth in care who have or are suspected of having FASD and who are not eligible for Community Living BC. Include in the program the following features:
 - Individualized plans designed to maximize independence and smooth the transition to the adult system of supports by age 24;
 - Assignment of a key worker to provide case management services and assist the youth, his or her family and other significant community supports in navigating the adult service delivery system;
 - Graduated levels of support based on an individualized assessment of need and flowing from the individual's transition plan developed in accordance with the Ministry of Children and Family Development's service standards;
 - A budget to fill gaps in services, to be allowed by the Ministry of Children and Family Development on the basis of relative need;
 - Accessible supported housing options;

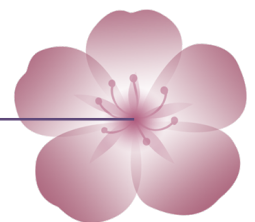


- Director access to employment training programs delivered through the Ministry of Employment and Income Assistance;
- When the youth reaches age 24, a plan that addresses the continuity of services beyond age 24 (Child and Youth Officer for British Columbia, 2006, p. v-vi).

Turning to the Manitoba context a more recent paper by Fuchs, Burnside, Marchenski and Mudry (2008), which examines the issue of adolescents with FASD transitioning out of care, was published through the Centre of Excellence for Child Welfare. In examining transition plans and factors evident in the placement histories of youth with FASD leaving care, the Fuchs and his colleagues provide a descriptive analysis of closed child in care files for 27 former permanent wards, aged 16 or older, who had been diagnosed or were suspected of having FASD. Their findings reveal that this particular group of individuals had experienced anywhere from 1 to 20 placements while in care. The authors' further state that the longest placement for these youth lasted on average 6.5 years and their mean age at the end of their longest placement was 15.3 years. The first placement was often recorded as the longest placement and that placement breakdowns occurred most often in adolescence. Transitional plans were made for some of the young adults in this group and that generally these plans involved extended care beyond 18 years but for less than one year. The file review indicated that comprehensive planning for only three youth transitioning out of care was. Also, it was noted that in addition to multiple placements, these youth had experienced involvement with multiple workers with the average number of workers being around six.

The factors identified by Fuchs et al above clearly indicate an increased risk for poorer outcomes for youth transitioning toward adulthood. The authors noted that while placements tended to be stable in the early years of placement they became increasingly unstable as children aged into adolescence. It is this stability factor which becomes a critical element in their education and transitional plans for independence. This later instability also reduces the chances these young people will have in establishing and maintaining enduring relationships with foster parents or teachers who might serve as advocates and mentors. The authors concluded with recommendations in four areas:

1. *Transitional Planning* – the authors indicate that the Manitoba protocol for transitional planning for children with disabilities reaching the age of majority is well developed and comprehensive, however the administrative database for determining the degree to which the protocol is used for children leaving care, is not adequate.
2. *Placement Factors* – the instability of placements for the majority of this sample challenges both school achievement and the creation of lasting relationships. The authors indicate that this needs to be addressed through enhanced training and support for foster parents or through the creation of alternate resources for placement.
3. *Extending Care* – extension of care provisions were also flagged by the authors as being minimally used in giving those with FASD additional time to mature and prepare for adulthood. Raising the age at which youth must leave care to more accurately reflect the reality for those living with parents has been recommended by others and is echoed by the authors of this report. This would be of particular benefit to youth coping with FASD.



4. *Services for Individuals Living on Reserve* – lastly, the services that do exist for those with disability are available only for persons living off reserve. Children on reserve the authors note remain disadvantaged in terms of services. The lack of on-reserve services means that many youth with FASD leaving care must choose between obtaining whatever services they can and living with the support of extended family. The right to reasonable services should be recognized and must be made available for all Manitobans as Fuchs et al emphasize.

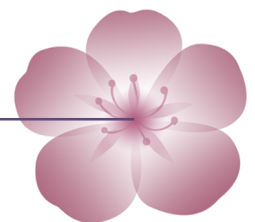
What is evident from the limited research on young people with FASD is that when we fail to recognize and understand the underlying needs of this population as they move toward independence we set them up for failure in adulthood. It is clear is that there is an enormous influx of adults into the populations of those most marginalized and disenfranchised in our society. This includes the homeless, the incarcerated, the mentally ill, and those with addictions. They now overwhelm service systems that span across several jurisdictions —health/medical, education, justice, social services, housing, employment – that are ill equipped to deal with the complex needs of individuals with FASD (McKechnie, 2000).

Best practices for servicing this vulnerable population was summarized by Gibson (2003) in a report to the Calgary Fetal Alcohol Network as a result of forum on youth with FASD transitioning toward independence. Youth with FASD who are transitioning from care toward independence need significant support in achieving: independence, employment, education, community inclusion and residential care. Gibson outlines a number of ideas that were generated by leaders, community members, and practitioners who work with young people with FASD. Gibson noted that for all individuals life transitions occur and in most cases individuals experience these transitions in interconnected and interrelated ways and that this should be no different for youth with FASD lives. She concludes that support, better services and individualization (or person centered approaches) are important elements of best practice approaches in assisting young people with FASD as they transition toward independence.

The next part of this review highlights research that reflects on the secondary disability issues that may arise for young individuals with FASD who do not receive early diagnoses or intervention before leaving care and the impact this is having on various societal systems and services, but particularly on that of the criminal justice system.

Secondary Disabilities

Longitudinal research on alcohol and pregnancy conducted in the United States by Streissguth, Barr, Kogan and Bookstein (1996) identified a number of serious lifelong problems experienced among youth and adults with FASD. Children with FASD are at risk of developing other problems when their original challenges are allowed to worsen without supports and resources. They coined these challenges and problems “secondary disabilities.” Primary disabilities are those the child is born with. Secondary disabilities develop as a result of failure to properly deal with the primary disabilities. Secondary disabilities tend to arise in instances where young people with FASD experience behavioural and mental health problems in adverse social environments. In people with FASD the primary disabilities of permanent organic brain damage are often hidden, leading schools, families, the justice system and society at large to expect normal behavior and reasoning. Without a low IQ score, obvious mental illness



or physical signs of birth defect, societal protection is lacking and blame or punishment is all too often the only response.

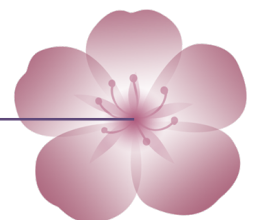
In other words secondary disabilities are those that are not present at birth and occur when societal systems necessary to meet the needs of this population are not in place (Lutke and Antrobus, 2004). This happens for instance when the health system fails to diagnose individuals or when the education system fails to find innovative ways to teach students with FASD (Gammon, 2002). Gammon further noted that “when caregivers are unable to provide stable homes because lack of skills, training or respite, or when there is no place in the job market able to cope with the supervision needed to employ adults with fetal alcohol related disabilities.”

The resulting secondary disabilities associated with FASD (if intervention doesn’t happen at early age) have been identified Streissguth, Barr, Kogan and Bookstein (1996) as including:

- Mental health problems;
- Disrupted school experiences – (suspensions, expelled or dropped out);
- Trouble with the law;
- Confinement (including inpatient treatment for mental health or drug/alcohol problems or incarceration for a crime);
- Inappropriate sexual behaviour (exploitation);
- Victimization;
- Alcohol and drug use problems;
- Needing dependent living situations;
- Problems with employment; and
- Problems with parenting.

Diane Malbin (2004) calls secondary disabilities defensive behaviours, which come about when there is a chronic “poor fit” between the person and his or her environment. Malbin states that defensive behaviours are normal protective reactions to frustration and are helpful cues for identifying points of intervention. These secondary disabilities often develop in early childhood and are patterns of behaviour by the time the child reaches adolescence. Secondary disabilities can be prevented when a good fit is provided. Malbin provided the following list of examples for identifying defensive behaviours in youth who exhibit signs of FASD:

- Inappropriate humor, class clown.
- Pseudo-sophistication; may echo words, phrases, manners, and dress in order to “pass” as competent beyond their actual ability, often to their detriment.
- Fatigued, irritable, resistant, argumentative.
- Anxious, fearful, chronically overwhelmed.
- Frustrated, angry, aggressive, destructive.
- Poor self concept, often masked by unrealistic goals or self-aggrandizement.
- Isolated, few friends, picked-on.
- Family or school problems including fighting, suspension, or expulsion.
- May run away, have other forms of avoidance.
- Depressed, may be self-destructive, suicidal (Malbin, 2004, 56).



There are protective factors that can influence the occurrence of secondary disabilities. These protective factors were also examined in the 1996 longitudinal study that was conducted by Streissguth and her colleagues in Seattle, Washington (1996). They found that being male and/or older than 12 years increased the likelihood of disruptive school experiences, trouble with the law, confinement (in a hospital or prison) and dependent living. There were eight “universal” factors identified that decrease the adverse impact of secondary disabilities. These include, from strongest to weakest, the following:

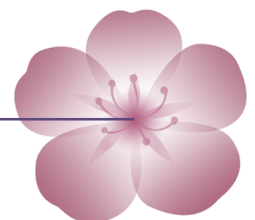
- Living in a stable and nurturing home for over 72% of life;
- Being diagnosed before the age of 6 years;
- Never having experienced violence against self;
- Staying in a stable living situation on average for more than 2.8 years;
- Experiencing a good quality home from ages 8 to 12 years;
- Not living in poverty; and
- Having applied for and been found eligible for supports from the Division of Developmental Disabilities⁶.
- Having a diagnosis of FAS (rather than FAE); and
- Having basic needs met for at least 13% over the course of their lives.

These protective factors reduce the likelihood of experiencing secondary and are directly associated with a stable and nurturing home life during childhood (Streissguth, 2001). These findings appear to suggest that with appropriate interventions, it may be possible to reduce the rate of secondary disabilities experienced by individuals who are FASD affected (Burd, Selfridge, Klug & Juelson, 2003; Clark, Lutke, Mines & Ouellette-Kuntz, 2004).

Surprisingly, Streissguth found higher rates of secondary disabilities in individuals who had FAE rather than FAS and who had an IQ higher than 70. She speculated that FAE individuals, who lack the biomarkers of individuals with full FAS, are not diagnosed as early, and do not receive developmental disability services to the same extent as FAS individuals (Mitten, 2004). IQ alone is not sufficient criterion for determining the need for support services for individuals affected by FASD. While some individuals may appear to have a higher IQ, they may be experiencing difficulty performing day-to-day activities (Clark, Lutke, Mines & Ouellette-Kuntz, 2004). Streissguth’s primary conclusion from this study was a strong recommendation that early diagnosis be made available wherever warranted, so that support services could be mobilized, appropriate educational and parenting practices could be implemented, and self-image could be enhanced rather than continually eroded (Streissguth & Kanter, 1997).

Clark, Lutke, Mines, and Ouellette-Kuntz (2004) state that within Canada there hasn’t been as much research conducted on the extent of secondary disabilities among young adults with FASD and its impact on the Canadian health, social and justice service systems. As a result, Clark and her colleagues set out to conduct a preliminary study in 2002 to determine the demographic and secondary disabilities profile among adults with FASD living in the lower mainland, Okanagan and West Kootenay regions of British Columbia. Two categories of participants were involved in this study: (1) adults 17 years and older with

⁶ This is a community living service in Washington State that includes access to case managers, job placement, job coaching and shelter.

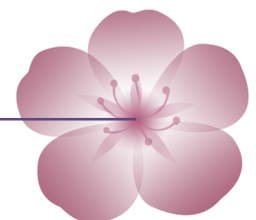


FASD and (2) “caregivers” or friends, family and/or a support worker identified by the adult with FASD. The lower age limit of 17 was chosen as it was identified as the age when transitioning out of care services begin. Caregivers completed a written survey and participated in a telephone interview. The written survey asked demographic characteristics and about the presence or abuse of a number of secondary disabilities. The telephone interview was based on questions to a “functional assessment” tool. This tool is used by the BC Ministry of Children and Family Development to assess level of care needed by an individual and can be used by individuals who are not trained psychologists.

A total of 62 clients (or 55%) diagnosed as having FAS or FAE participated in the Clark et al study. The discussion revealed that only 34% of the participants with FASD had an IQ below 70 which meant the majority of participants tended to be of average intelligence. But the authors noted that 81% required a moderate to high level of care indicating there were severe deficits in those adults’ adaptive skills. The authors noted that IQ alone is not sufficient criterion for determining the need for support services among persons with FASD as they may have great difficulty performing day-to-day activities while still possessing a measured IQ of 70 or greater (an individual with a measured IQ below 70 is considered to have mental retardation). The caregivers noted that the participants with FASD are “vulnerable to manipulation” (92%) which has been identified in other research as a significant factor among adults with intellectual disabilities who are involved with the criminal justice system. The authors also note that the participants with FASD in this study experienced high rates (87%) of verbal, physical and/or sexual abuse. Caregivers indicated that the most common disability experienced by adults with FASD was a mental health diagnosis (92%) and disrupted school experiences (61%). The most common mental health diagnosis mentioned by caregivers was attention deficient disorder / attention deficit hyperactivity disorder (65%) following by depression (47%) and panic disorder (21%). Clarke et al also indicated that other diagnoses included post-traumatic disorder, oppositional defiance disorder and bipolar disorder. 45% were found to have been involved or in trouble with the law (p.5-6). The authors concluded that the results of their Canadian study were very similar to that carried out by Streissguth and colleagues in the Seattle longitudinal study. However Clark et al. noted two differences. The overall prevalence rate for secondary disabilities among adults with FASD they noted was slightly lower in the Canadian study but suggested this difference might be because Canada’s universal health care system. The other difference was in the percentage of clients with at least one mental health diagnosis. The Canadian study revealed the co-morbidity of mental health with FASD was extremely high at 92% compared to Streissguth et al finding’s at 30-40% for the same secondary disability. Clark and her colleagues noted there could be many reasons for this:

- The susceptible genes for alcoholism and mental health problems may be the same;
- Women with mental health problems, such as schizophrenia, may use alcohol as self-medication for the symptoms of the mental health problems or the side effects of the anti-psychotic medications;
- The mental health problems (e.g. ADHD) may actually be a component of FASD and not a separate diagnosis; and
- The lack of support and understanding given to adults with FASD likely contributes to an increased prevalence of mental health problems such as depression (p. 11).

Clark et al (2004) note that there is insufficient evidence to determine what the nature of the relationship is between mental health problems and FASD. Living with a caregiver was considered a key



resource for individuals living with FASD and that that factor alone was significantly associated with FASD affected adults not getting into trouble with the law (p.11).

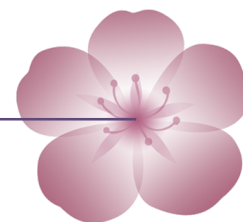
As with any developmental disability, children and youth with FAS and their families will require a range of support programs and services throughout their lifetimes (Coles, 2003). Young person in care who have been diagnosed with FASD tend to need extra supports or an external brain (first used by Dr. Sterling Clarren), who are characterized as family members, friends or a professional who can help the young person plan, organize and compensate for deficits in executive functioning (planning ability) (Kellerman, 2003; Slade, 2004). Building strong supports early on will help reduce the likelihood of secondary disabilities (Streissguth, et al, 1996). In preventing secondary disabilities Rutman and colleagues (2005) note that there is increasing recognition that it is other people – family, professionals, policy makers and communities – who need to change and make accommodations rather than FASD affected individuals. Rutman, et al (2005) quoting Brenda Knight, a psychologist with expertise in working with FASD-affected people and their families and caregivers, note that:

One of the problems with Fetal Alcohol Syndrome isn't the person with Fetal Alcohol Syndrome. It's with the people around them, having to understand about (FASD). (Thus) we can modify who we are, so they can understand us (p.4).

The effects of FASD are manifested throughout the individual's lifespan (Streissguth, Barr, Bookstein; Zevenbergen & Ferraro, 2001). Infants who have been exposed to alcohol may show decreased arousal, sleeping problems, irritability and feeding difficulties. Difficulties with speech, language development, and attention span are often identified in preschool years. Poor attention, impulsivity, and hyperactivity often persist throughout childhood and adolescence, leading to behavioural issues that arise in school settings, which only exacerbate the academic challenges that stem from learning disabilities and other cognitive impairments related to FASD. These academic and social difficulties often contribute to low self esteem, conduct problems and delinquent behaviors in adolescence. As adults, individuals with FASD are vulnerable to mental health problems, conflict with the law, alcohol and drug addiction, including problems with employment, finances and homelessness, (Streissguth, Barr, Kogan, & Bookstein, 1996; Lutke & Antrobus, 2004). One area where secondary disabilities have become more apparent is within the realm of criminal justice system. An increased awareness of youth and adults with FASD coming into contact with the law have begun to receive the attention of judges, lawyers, legal academics, physicians and others involved in research related to the legal system (Henteleff, 2002; Mitten, 2004; Moore & Green, 2004; Stade, Clark & D'Agostino, 2004).

Criminal Justice Involvement

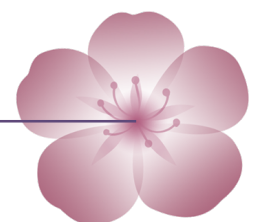
Dr. Anne Streissguth, of the University of Washington is a leading researcher in the area of FASD. Her research on the damage to the central nervous system suffered by alcohol exposed children indicates that these children may display a number of characteristics of central nervous system damage such as attention deficit hyperactivity disorder (ADHD), attention deficits, learning disabilities, mental retardation, gross motor and fine motor problems, poor impulse control, problems with social perception, and severe behaviour problems (Streissguth, 1997). In the area of cognitive difficulties, these children often experience processing delays, misinterpreting signals that the senses receive in



processing and storing such information, difficulties in accessing information and difficulties in expressing themselves. Most importantly, the alcohol affected child has trouble with many aspects of reasoning. In the result they have difficulties in problem-solving, memory, and trouble with organizing thoughts and actions. They also suffer from severe difficulties in overall language and attention span. There are general problems with distractibility, causing them to react impulsively to their environment. In the result, many of these children manifest severe difficulties in school resulting in a high early dropout rate and high delinquent activity if they do not have structured support throughout their lives (Streissguth, 1997). Some of the most crippling secondary disabilities that people with FAS/FAE face include mental health problems, disrupted school experience, inappropriate sexual behavior, trouble with the law, alcohol and drug problems, and difficulty caring for their children, as well as homelessness (Conry & Fast, 2000). Impressions from some judges, lawyers, physicians, and others in the legal system indicate an increasing awareness that youth and adults with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) are coming into conflict with the law. The neurological damage caused by prenatal exposure to alcohol affects the whole brain and may result in an increased susceptibility to criminal activity and victimization (Henteleff, 2002; Fast et al., 1999).

The most pressing legal issues arise from the cognitive and behavioural expressions of the disorder (Verbrugge, 2003). The characteristics of youth affected by prenatal alcohol exposure can lead them to become criminalized. Some of the characteristics exhibit by youth with FASD include: impulsivity, poor judgment, lack of understanding consequence of behaviour, inability to learn and generalize from past mistakes, poor and fluctuating memory so confusion may occur, they are easily suggestible and manipulated, poor social skills / abilities but desire to socialize, and difficulty with concepts of time and money (poor math skills). It is vital to understand the individual offender in order to address the underlying reasons for criminal behavior. Individuals with FASD often come from dysfunctional backgrounds, and may have mental illnesses and substance use disorders. A comprehensive medical-legal report, prepared by a professional experienced with FASD, can help judges and lawyers understand how complex the interactions are among brain damage, genetics, and the environment. The person with FASD can be misunderstood in court, victimized in jails, and mismanaged in the transition back to the community, unless those working with the individual are aware of FASD and its implications (Fast & Conry, 2004). As well the literature indicates that youth with FAS/E often have better expressive language skills than receptive language skills so they appear to understand more than they actually do (Verbrugge, 2003).

A 2000 report, titled *Fetal Alcohol Syndrome: Understanding its Impact* prepared by Fred Boland and Michelle Duwyn of the Psychology Department at Queen's University and Ralph Serin of the Research Branch Correctional Services Canada, reconfirmed all of the conditions resulting from FASD, their manifestations during infancy, as school-aged children, in adolescence and in adulthood, ultimately resulted in a very high incidence of trouble with the law (Boland, Burrill, Duwyn & Karp, 1998). As noted in the report, the first report in Canada estimating the incidence of FAS for an entire province was conducted in Saskatchewan and published in 1996. All cases of FAS who were born in Saskatchewan prior to January 1, 1993 were studied. Of these cases so identified, 86% were of Aboriginal descent. In fact the authors noted that due to the likelihood of the number of cases being under-diagnosed throughout the province; their incidence statistics were under-estimated. The report further pointed out that all epidemiological studies have concluded that FAE has an incidence of 3 – 4 times higher than FAS. A study in the Yukon Territory and in British Columbia, as noted in this report, indicated a 10.9 to 1 ratio



of Aboriginals with FAS in comparison to the Caucasian population. Given that aboriginal offenders are considerably over-represented in the federal justice system and having in mind the correlative factors previously noted, it is clear that the high rate of FAS/FAE experienced by the Aboriginal population is a contributing factor to their being in conflict with the law (Boland et al., 1998; Boland, Duwyn, & Serin, 2000).

The Department of Justice Canada also explored the connection of FASD to the youth criminal justice system which resulted in a discussion paper reviewing at length the case law in Canada where young defendants were diagnosed with FASD and was written by Paul Verbrugge (2003). This discussion paper reviewed the construction of FASD, the fitness of FASD individuals to stand trial before the courts, criminal intent, proportionality of court interventions and sentencing options. The last section of Verbrugge's report focuses specifically on bridging the youth criminal justice system with other social service support systems. Verbrugge stresses the importance of working collaboratively with social service systems that all fall within the same jurisdiction so that individuals who have FASD are identified so that the appropriate responses can be tailored to meet their needs. Verbrugge does note that there are problems with implementing standardized screening and diagnostic tools as well as issues of consent as a FASD diagnosis could have significant impact on how a youth is treated by the system. The primary focus of this last section looked at section 35 of the Youth Criminal Justice Act (YCJA) as it was intended to help integrate the social welfare and justice systems. Section 35 reads as follows:

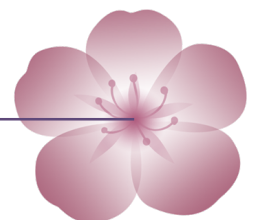
35. In addition to any other that it is authorized to make, a youth justice court may, at any stage of proceedings against a young person, refer the young person to a child welfare agency for assessment to determine whether the young person is in need of child welfare services.

The section is viewed as vague by legal scholars as it is not clear as to what is meant by "child welfare agency." The term could be narrowly interpreted to mean "child protection services" or read broadly to "include programs and promote social welfare, including mental health services, and education." Other scholars provided the following interpretation of the purpose to section 35 of the YCJA:

The YCJA reflects a basic policy position that the criminal justice system should not be used as the primary way of addressing the child welfare needs of youth ...

A criminal justice intervention may attempt to address a youth's child welfare needs as part of a sentence that is intended to promote the rehabilitation of the youth. However, the sentence must not exceed what is a fair and proportionate response to the offence that the youth has committed. The child welfare needs of the youth may be well beyond the proper scope of the criminal law or may not be directly relevant to the offence committed.

Section 35 is a legislative reminder to judges that the child welfare needs of youth in conflict with the law are important and should not be ignored simply because they cannot be addressed through the criminal law. If a judge believes that a young person before the court may have child welfare needs that are beyond the proper scope of the criminal justice system, it is in the interests of the young person and of society for the judge to bring his or her concerns to the attention of the child welfare authorities ... (Verbrugge, 2003, p. 29).



Other sources exist that have been created to specifically address the connection between FASD and the youth criminal justice system include the development of a resource guide to assist police in recognizing signs of Fetal Alcohol Spectrum Disorders when dealing with young persons suspected of having FASD (See “Fetal Alcohol Spectrum Disorder: FASD Guidebook for Police Officers” at <http://www.asantecentre.org/pdf/latestfasguide.pdf>). The publication is being used primarily to promote awareness, identification, appropriate intervention and prevention of FASD by police officers who are front-line workers who will often come into contact with a high number of victims, witnesses and suspects who have been affected by alcohol prenatally (Laporte, McKee, Lisakowski, Chudley & Conry, 2002).

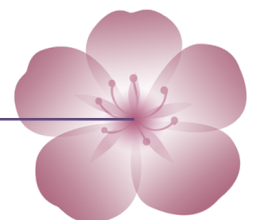
The literature is just beginning to explore the connection of FASD on youth delinquency and its impact in the youth criminal justice system. Much about what is known regarding the social and behavioural expressions of FASD is attributable to the work of Streissguth et al, although other researchers and advocates have begun to focus on this issue (Fast et al., 1999; Malmgren & Meisel, 2004; Henteleff, 2002; Bala, 2003); however there remains very little literature on the direct role social services may have to FASD and delinquency in relation to the Youth Criminal Justice system. Verbrugge (2003) states that given the current state of the literature, there is an opportunity to make a significant contribution to the knowledge base through promoting research on FASD and its connection to the youth criminal justice system. Important research questions Verbrugge suggests would include:

- a. Looking at the prevalence of FASD amongst youth in the criminal justice system (with special attention given to gender differences)
- b. Looking at what are the severity of cognitive deficits in relation to legal standards (e.g. what percentage of FASD accused are unfit to stand trial?)
- c. Looking at the temporal stability of cognitive deficits from youth to adulthood, and
- d. By exploring the community treatment options and their relative effectiveness.

Verbrugge states that it is important to invest in sound research on FASD to prevent the formation of stereotypes and the need to be cognizant that there are individual differences amongst people who have been diagnosed with FASD as this will contribute to better policy options for youth who have FASD.

There is a paucity of research that examines systematically the cognitive and behavioural deficits associated with FASD among adolescents. What does exist is based upon anecdotes and descriptive studies. Verbrugge (2003) cautions the importance of investing in research on FASD as reliance on anecdotal information often results in the formation of stereotypes which ignores the reality of individual differences amongst individuals who have been diagnosed with FASD.

One of the first Canadian studies to explore the prevalence of youth with FASD involved with the justice system was undertaken by colleagues Conry, Fast and Loock (1999). Their study involved 67 youth between the ages of 12 and 18 years who were remanded to an Inpatient Assessment Unit of the Youth Forensic Psychiatric Services in British Columbia. Of the 67 youth remanded to the unit, 3 were diagnosed as having full fetal alcohol syndrome while the remaining (64) were diagnosed with having fetal alcohol affects (FAE or partial FAS). The percentage of occurrence among the 3 diagnosed with full FAS was noted to be 3 to 10 times the accepted worldwide incidence for this disorder. The percentage

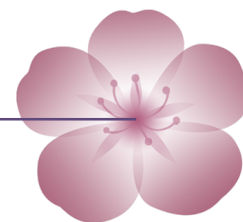


of the remainder with alcohol-related diagnosis was considered to be 10 to 40 times the accepted worldwide incidence. These early findings solidify the disproportionate representation of youth with FASD and/or cognitive impairment in the juvenile justice system (Conry, Fast & Look, 1997).

Once in the system, youth with FAS/E generally keep cycling through for curfew violations, associating with the wrong people, drug and alcohol consumption, truancy, shoplifting, or minor sexual offenses (often a matter of accepting the wrong invitation). Normal teens, once they have been caught and want to regain their autonomy, understand how to curb or hide these impulses long enough to get off probation. People with FAS/E do not have the ability to plan for their future, curb their impulses or, ultimately, regain their autonomy. And to cement their fate, they have not been graced with the ability to own up to their mistakes (Page, no date).

Whether there is a diagnosis or not, there is a growing awareness that young people with FASD who come into contact with the youth justice system may not understand and have difficulty following probation and court orders (Conry, Fast & Look, 1997). FASD affected youth, for the most part, are unable to benefit from programs designed for youth who do not have disabilities and their human rights as a result are being jeopardized (Henteleff, 2002). The justice systems' traditional approaches are based on the assumption that most youth understand and appreciate the consequences and act of their own free will; most programming tends to presume typical adolescent cognitive abilities. Such approaches, unfortunately, do not always work for young people with FASD (PLEA Community Services Society of British Columbia and The Asante Centre for Fetal Alcohol, 2005). Yude Henteleff, a Manitoba based advocate on the human rights of individuals with FAS/FAE, quoted at length from a report published out of the Northwest Territories that persons with a learning disability are least likely to have their disability named or assessed, diagnosed and dealt with. The report dealing with the reasons for a disability notes that 50% of those who have what are described as "intellectual disabilities" are born with it as a result of FAS/FAE. What is clear is that individuals, particularly youth, are struggling to be understood for the disabilities they have. These disabilities are seldom recognized, and individuals with FASD are seldom treated effectively. Attending to basic human rights, civil rights and criminal justice for these individuals is increasingly difficult to do (Streissguth, 1998; Henteleff, 2002). Hornick, Paetsch, Bertrand and Jacobs (2008) noted in their literature review that many barriers to clients (both youth and adult) involved in the criminal justice system. These include barriers to obtaining legal assistance and information, participation in the legal system, obtaining non-legal support services to participation in legal reform to ensure access to services and justice for those with FASD who may be engaged in the justice system.

A number of articles have addressed the need for the justice system which services incarcerated youth and adult populations to develop screening and assessment procedures and for determining whether youth and adult inmates are affected by FASD (Burd, Selfridge, Klug & Juelson, 2003; PLEA Community Services Society of British Columbia and The Asante Centre for Fetal Alcohol, 2005) along with identification of the training needs of staff employed within both the youth and adult corrections systems for understanding this issue among prison populations (Leischner, 2002). Other available research resources center on training initiatives being undertaken across Canada. These include: probation officers working with adult offenders in Alaska, a Train the Trainer FAS workshop in Alberta, half day training initiatives for RCMP in Manitoba and FAS training incorporated into correctional services training both Yukon and the Northwest Territories. Initiatives in BC include a one-day training session on FAS for youth custody and youth probations officers through the Justice Institute of BC. The



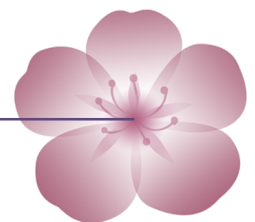
Public Health Agency of Canada conducted a national scan on the volume and nature of educational and training activities related to FASD (Public Health Agency of Canada, 2006). The scan serves as a starting point in mapping where training is happening within Canada, to whom it is being directed, and the topics being addressed including gaps in knowledge topics and training populations. As alluded to earlier in this review, an Aboriginal component to the scan on FASD training was conducted jointly by the First Nations Child and Family Caring Society and Paukuutit Inuit Women of Canada. The Aboriginal companion report captures information about the kinds of FASD services available in First Nations and Inuit communities and, the extent of FASD training opportunities available to First Nations and Inuit service providers and community members (Irvine & Vincent, 2006).

The secondary disabilities of people with FASD are costing the taxpayers far more than any other disability. FASD and its related secondary disabilities exert a significant impact on Canada's economy. Individuals affected by prenatal exposure to alcohol often require specialized education, mental health attention, care and facilities throughout their lifetime and tend to over utilize systems and services (Loney et al., 1998). In addition, the many secondary disabilities that arise impact individuals' ability to live independently, function according to societal norms and remain gainfully employed. Thus, the economic cost of FASD is significant. The importance of diagnosing early cannot be stressed enough (Sonnander, 2000).

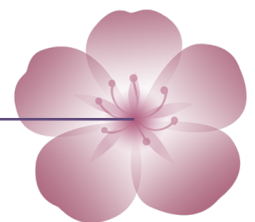
Areas for Further Study

There is a plethora of materials focusing on numerous aspects of the medical and social conditions related to the issue of fetal alcohol spectrum disorder. Sifting through these resources has been a complex exercise. The following areas identified as needing further research were gleaned from the material consulted for this review. These suggestions are by no means meant to be a definitive list and merely serve as suggestions for understanding an otherwise complex reality:

- Child's awareness of having FASD – this understanding is not reflected in the literature but seems to be an area that needs further examination;
- Understanding of how biological children of caregivers might be affected and impacted by their parents' decision to raise children with FASD. Moreover how important are these biological children to the development of children with FASD?
- Understanding the needs of the foster and adoptive parents who take on the task of raising children with FASD;
- Further understanding about what motivates individuals to foster and/or adopt children with alcohol-related disabilities;
- Individuals with FASD also become parents but research on the challenges faced by adults with FASD who are parents is very limited and perhaps non-existent within the Canadian context. Understanding the barriers faced by adults with FASD who become parents;
- Visitations with birth family – the literature does not address the role of the family and communities of origin in the lives of children/youth affected by FASD – but seems to be an area that might be of importance given that the majority of children/youth with FASD live in foster care situations and may be Aboriginal;



- Understanding the financial consequence to caregivers (both birth and foster) looking after children with FASD;
- Understanding the financial costs to various systems (primarily understanding the costs to child welfare agencies over the course of FASD children's lives in care);
- Understanding the rates and reasons of foster home breakdown for children and youth with FASD;
- Understanding the issues that lead to breakdown in placements of children in care who have FASD;
- An additional area of exploration would be issues related to the vulnerability of children with FASD that struggle with making and maintaining emotional relationship with others;
- Understanding the issues faced by parents who themselves were prenatally exposed to alcohol may or may not have been diagnosed with FASD;
- Parents, whether they are biological, foster or adoptive, are the main advocates for FASD affected children and adolescents and they need assistance to carry out the difficult but important task of raising children and adolescents who are affected by FASD spectrum of disabilities. This is a lifetime disability and the role of parents as the "external brains" for these children and adolescents won't likely subside even long after the children and adolescents in their care reach the age of majority. Further research needs to be conducted on understanding the role of parents in the lives of FASD affected persons beyond attaining the age of majority.
- Research into the prevalence of FASD in the offender population and more specifically the Aboriginal offender population and understanding of how many have been in child welfare care;
- What are the social determinants of health for women of child bearing ages in Manitoba who might have substance abuse issues? Moreover, understanding how poverty contributes to the prevalence of FASD among women living in poverty.
- Shared parenting approach to practice has been highlighted in this review. Shared parenting approaches provide unique opportunities to both social workers and foster parents in providing nurturing to birth parents and children alike but that training and support for supervisors, managers, line-protection workers and foster parents is required to facilitate this change. Such an approach offers a "modern approach" to child protection and further research and evaluation of such approaches will be needed to determine whether this particular approach is a best practice approach to utilize in the child welfare context;
- Further research needs to be conducted with the populations who have been incarcerated in the criminal justice system to understand why these individuals have been failed by various systems that they have been involved with throughout their young lives.



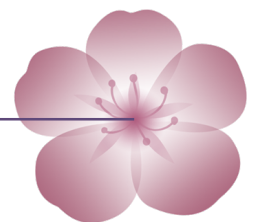
Summary / Conclusion

Fetal Alcohol Spectrum Disorder (FASD) encompasses a range of conditions that are caused by maternal alcohol consumption during pregnancy, which has lifelong implications for the affected person, the family, and society. Considered to be a completely preventable condition (Zevenbergen & Ferraro, 2001), the adverse effects of maternal consumption of alcohol have been noted throughout history but were first described as a pattern of disabling effects under the term 'Fetal Alcohol Syndrome' in the early 1970s. Although there are no national statistics on the rates of FASD in Canada, the incidence of FASD in Manitoba has been estimated at 7.2 per 1,000 live births (Williams, Obaido & McGee, 1999) to as high as 101 per 1,000 live births (Square, 1997). American incidence rates of 9.1 per 1,000 live births have been reported (Sampson, Streissguth, Bookstein, Little, Clarren, Dehaene, Hanson, & Graham, 1997), but it should be noted that diagnosis of FASD may be delayed or missed entirely, affecting the accuracy of such statistics (Chudley, Conry, Cook, Loock, Rosales, & LeBlanc, 2005). Because of the range of effects as a result of prenatal alcohol exposure, diagnosis of FASD can be complex (Chudley, et al, 2005; Zevenbergen & Ferraro, 2001). Diagnosis is often most easily made between the ages of 4 and 14 (Lupton, Burd, & Harwood, 2004), but early diagnosis and intervention is recommended to ameliorate the negative effects of FASD, through the provision of cognitive stimulation, speech and language therapy, educational supports, and other interventions (Sonnander, 2000).

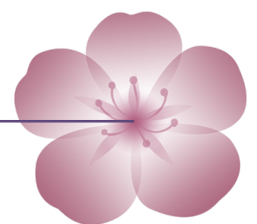
In addition to the personal implications for a person affected with FASD, the societal impact of FASD is profound (Lupton, Burd, & Harwood, 2004). Individuals with FASD often require high levels of medical care, residential services, special education supports, adult vocational services, and other social services throughout their lifetimes. The increased risk for deleterious outcomes in adulthood as a result of FASD (i.e. unemployment, homelessness, poverty, criminal activity, incarceration, and mental health problems) all have a social cost in terms of the support services, organizational structures, and associated financial costs that must be provided to respond to the needs of this vulnerable population (Lupton, Burd, & Harwood, 2004).

Given the difficulties facing individuals affected by FASD, it is not surprising that families caring for a child with this condition experience significant challenges. Little research exists with regard to the needs of families parenting a child with FASD (Wilton & Plane, 2006), although there is a growing body of literature examining the experiences of substitute caregivers (foster parents and adoptive parents) who increasingly are responsible for the care of children with FASD through the child *welfare system* (Barth, 2001; Brown, Bednar, & Wiebe, 2004; Brown, Sigvaldason, & Bednar, 2006; Gammon, 2002; Jones, 2004; McCarty, Waterman, Burge, & Edelstein, 1999). With parental substance abuse and its relationship to child abuse and neglect being one of the major reasons for the involvement of the child welfare system with families (Barth, 2001; Bartholet, 1999), it is not surprising that many children with FASD come into out-of-home care, often on a permanent basis (Jones, 1999).

In summary, Fetal Alcohol Spectrum Disorder is an area of significant concern in Manitoba's child welfare system, with 11% of all children in care having FASD. More than one third of the children in care with disabilities have been diagnosed with FASD. This is an entirely preventable condition, as it results from women drinking alcohol while pregnant. Its prevalence in the population of Aboriginal children

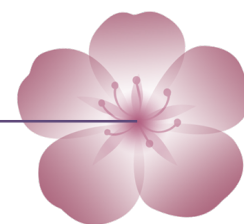


with disabilities, especially among First Nations children, indicates a strong need for establishing and expanding programs that emphasize the importance of not drinking any alcohol if a pregnancy is being planned, or, especially, during pregnancy. There is a strong need for such programs to be accessible and culturally appropriate (Irvine & Vincent, 2005).

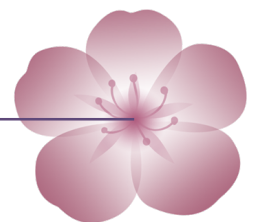


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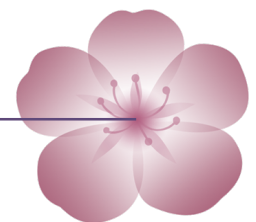
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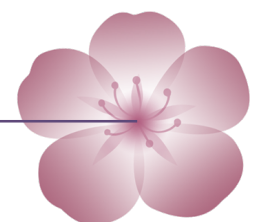
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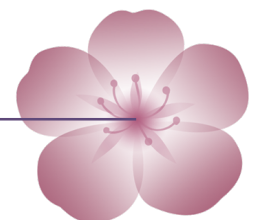
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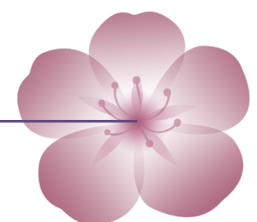
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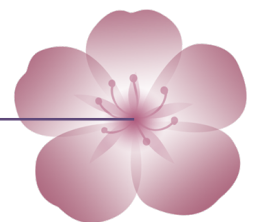
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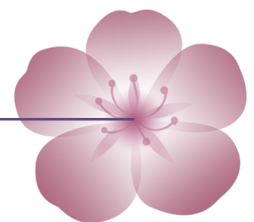
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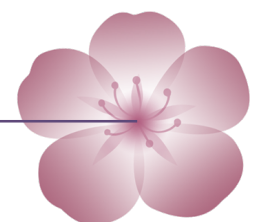
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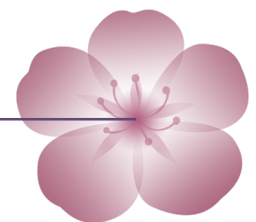
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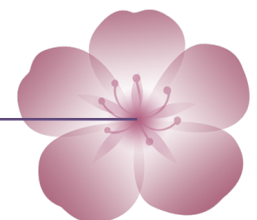
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<http://www.fasdconnections.ca/>
<http://www.fasdlane.com/>
<http://www.ccsa.ca/toolkit/introduction.htm>*
<http://www.fasdoutreach.ca/>
<http://www.ccsa.ca/ccsa>
<http://www.acbr.com/fas/index.htm>
http://www.hc-sc.gc.ca/fnih-spni/famil/preg-gros/intro_e.html

AMERICAN WEBSITES

<http://come-over.to/fasstar/faspix/1stGeneration.htm>
<http://www.fasdcenter.samhsa.gov/>
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