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# A Social Work student's developing understanding of Fetal Alcohol Spectrum disorder from medical and social perspectives and implications for practice

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## **A Social Work student's developing understanding of Fetal Alcohol Spectrum disorder from medical and social perspectives and implications for practice**

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### **Abstract**

*Research on FASD has focused on medical/scientific findings (Gallicano, 2010; Jones, & Smith, 1973; Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004). Continued medical research is thought to be helpful to our understanding of the origins of FASD and the interventions that help to address the psychosocial needs of persons with FASD. However, this paper stresses the need to also focus on the social aspects of FASD and the implications for human service workers who provide support for persons with FASD and their families. Gough and Fuchs (2006) indicate that although there is a growing prevalence of FASD-related disabilities, there is not a substantive knowledge base on child welfare practice in response to FASD. The need for human service workers to look beyond identifying a condition and addressing symptoms is emphasized. The author suggests human service workers need to prepare to work with children with FASD by reflectively appreciating the economic, legal, and cultural influences affecting persons as well as medically- and evidenced-based interventions.*

*Keywords: Fetal Alcohol Syndrome Disorder (FASD), medical perspectives, intervention, social support, human service workers.*

## Introduction

This literature review is a Canadian social work student's account of an academic learning experience about Fetal Alcohol Spectrum Disorder (FASD). FASD is a complicated problem garnering the attention of multiple perspectives. However, understanding FASD required, initially, exploring the topic from a medical and social perspective. Thus, the articles chosen for this review pertain to medical, legal, economic, and social issues associated with FASD, literature that demonstrates that FASD creates issues for society that require cultural considerations. The literature dates back to the 1970s when the syndrome appeared in North American medical literature, indicating FASD was first regarded as a medical problem, but slowly also became recognized as a legal, economic, and social justice issue. The knowledge learned about FASD resulted in considerations about the implications for practice by human service workers.

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a broad range of disabilities that are caused by prenatal exposure to alcohol (Alberta Human Services, 2012). Children with FASD may have significant abnormalities ranging from alteration in memory, judgment, and executive function to intellectual disability (Chudley, Conry, Cook, Looch, Rosales, & LeBlanc, 2005; Masotti, George, Szala-Meneok, Morton, Looch, Van Bibber, Ranford, Fleming, & MacLeod, 2006). Chudley et al. (2005) and Fast and Conry (2009) suggest it occurs in 1-3% of live births. Understanding about FASD evolved from a medical approach to include a social perspective. Acknowledging the limited literature available on how to support persons with FASD, and focusing on the implications of FASD for human service workers, this paper indicates there is a need for helping professionals to have a greater understanding of the social perspectives associated with FASD.

Jones and Smith (1973) first used the term, Fetal Alcohol Syndrome (FAS) to refer to the problems seen in infants born from alcoholic mothers. Later, the syndrome began to be understood as a spectrum of disorders, and thus, was renamed Fetal Alcohol Spectrum Disorder (FASD). Both terms are used in this paper in an effort to match the terms used by each author in the literature; otherwise, FASD is used interchangeably to mean both FAS and FASD.

As a social work student I have been influenced by an innovative course on FASD and Child Welfare Practice at the University of Calgary, Faculty of Social Work. The course entitled, FASD and Child Welfare Practice, taught by Dr. Dorothy Badry, a faculty member involved with the Canada FASD Research Network for many years, helped me to understand the distinct needs of children and youth with FASD. I learned that the needs of children with FASD who receive child welfare services differ from the needs of other children, primarily due to the challenges that have brought them into care. As a result of taking this course, I developed a broad understanding of the Canadian response to FASD from medical, psychological, economic, and social perspectives. I became familiar with practice-based concerns related to FASD and have since applied this learning in my social work practice.

## Medical perspectives

In the 1970s, emerging literature in North America focused on medical characteristics. Jones and Smith (1973) suspected alcohol contributed to problems in offspring. In writing about antiquity, Jones and Smith noted that “In Carthage, the bridal couple was forbidden to drink wine on their wedding night in order that defective children might not be conceived” (p. 999). They also draw our attention to a report submitted to the House of Commons in 1834 suggesting that offspring of alcoholic mothers were sometimes born with notably different physical features than offspring of non-alcoholic mothers. In their study, Jones and Smith noted several medical similarities between three infants born from mothers addicted to alcohol. These similarities included, but were not limited to, low birth weight and length, small eye openings, heart murmurs, joint and breathing problems, and clefts on the soft palate.

Root, Reiter, Andriola, and Duckett (1975) conducted a study on four children with the intent to see if growth abnormalities present in FAS could be caused by hormonal imbalances. All four children had heart murmurs. Three of the children were underweight and described as having similar facial features to the infants studied by Jones and Smith (1973). Root et al. concluded that growth abnormalities seen in the children were not caused by hormonal imbalances and suggested the children were underweight due to sub optimal nutrition and physically short in stature because of genetic factors.

Adding to the medical symptoms associated with pre-natal alcohol exposure, Stromland (1987) reported ocular abnormalities associated with FAS, suggesting up to 90% “of children suffering from the fetal alcohol syndrome have eye abnormalities, including malformation in the outer eye region, disorders of motility, and defects of different intraocular structures” (p.227). Stromland concluded there was an insufficient method to attribute abnormalities in children with FAS to a specific gestational period. In another study, Gabriel, Hofmann, Glavas, and Weinberg (1998) discovered alcohol in fact could disrupt and impair hormone levels in a mother and fetus. Additionally, Gabriel et al. suggested that growth hormones and insulin-related growth factors were also affected by alcohol, which offers a possible explanation for some of the growth related issues associated with FAS.

The link between FASD and epilepsy was strengthened by the work of Bell, Stade, Reynolds, Rasmussen, Andrew, Hwang, and Carlen (2010) who studied “the prevalence of epilepsy or a history of seizures in subjects with FASD” (p.1084). Bell et al. discovered a high prevalence of epilepsy (5.9%), compared to (0.6%) in the general population (Tellez-Zenteno, Pondal-Sordo, Matijevic, &Weibe, 2010). In one part of the study, 350 of the 425 were categorized by three specific FASD diagnoses; Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, and Alcohol Related Neurodevelopmental Disorder. Bell et al. found seizures were prevalent in all categories.

As a focus of this literature review the above medical symptoms and implications of FASD are important in the initial development of an understanding of FASD. Equally important, or more so, are the social and practice implications of FASD, beginning with a consideration of the interventions used presently in working with people who may have FASD.

## Interventions

Presently, there is no cure for conditions related to prenatal alcohol exposure, making FASD a lifelong disability (Gallicano, 2010). From a psychosocial perspective, persons with FASD face adverse life outcomes (Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004). Streissguth et al. noted that some of the psychosocial problems associated with FASD included “major disruptions in schooling, trouble with the law, inappropriate sexual behaviors, extensive confinements, and alcohol and drug problems” (p. 236). Challenging behaviors are addressed through structure and systematic teaching as potentially effective methods for children with FASD. A predictable environment supports a child diagnosed with FASD to better connect daily activities. Achieving a structured environment includes making a daily schedule and keeping it fairly consistent, striving for low amounts of ambiguity in instructional methods, and making the connections between different instructional methods consistent and clear. In addition, Kalberg and Buckley (2007) support teaching that decreases visual and auditory distraction with activities that are organized visually.

Illustrating the need for structure for children with FASD, Kalberg and Buckley (2007) indicate the school environment can be daunting and difficult to successfully navigate, academically and socially, making the school a negative experience for the child with FASD. Kalberg and Buckley suggest “helping the child to metacognitively understand his/her learning style and challenges may assist in the child’s ability to moderate his/her own behavior appropriately” (p. 284). They also promote structuring and systematic teaching techniques appropriately tailored to each child to create predictability and understanding for the student. The sense of safety, comfort, and confidence is thought to result in the child’s willingness to take more risks, resulting in increased skill development and a more positive sense of self.

Historically, research on FASD has focused on medical/scientific findings (Chudley et al., 2005; Gabriel et al., 1998; Gallicano, 2010; Jones, & Smith, 1973; Root et al., 1975; Streissguth et al., 2004; Strömberg, 1987; & Tellez-Zenteno et al., 2004). Although continued medical research is helpful to our understanding of the origins of FASD, it is also important to examine interventions that help to address social issues and the implications for human service workers who provide support for persons with FASD and their families. Human service workers who respond to the needs of children with FASD need to be knowledgeable and informed to promote good practice. We also need to understand the root causes of FASD to help resolve what may be a preventable social problem.

## Social perspectives

One way to obtain an essential understanding of how FASD has become a social concern is to view the development of FASD from a social, as well as a medical perspective. Socially, the use of alcohol historically influenced the development of FASD as illustrated in the following quote:

Parents gave it [alcohol] to children for many of the minor ills of childhood, and its wholesomeness for those in health, it appeared, was only surpassed by its healing properties in case of disease. No other element seemed capable of satisfying so many human needs. It contributed to the success of any festive occasion and inspired those in sorrow and distress. It gave courage to the soldier, endurance to the traveler, foresight to the statesman, and inspiration to the preacher. It sustained the sailor and the plowman, the trader and the trapper. By it were lighted the fires of revelry and of devotion. Few doubted that it was a great boon to mankind (Levine, 1983, p.115).

What the above quote suggests is that alcohol is an entrenched, and rightly or wrongly, celebrated characteristic of society historically. However, the effects alcohol has had on society are generally understood to not be entirely positive. For example, the social impact and destructiveness of alcohol and alcohol addiction presents critical issues within society, as noted in the following discussion about social challenges presented by FASD.

## International and national economic challenges

FASD is an international issue due to the global availability of alcohol and the economic costs associated with managing and preventing FASD-Related disabilities. Drabble, Poole, Magri, Tumwesigye, Li, and Plant (2011) wrote on the efforts of the United States, Canada, the United Kingdom, Uganda, Uruguay, and China to prevent FASD. The fact these countries include the world's two largest economies, the United States and China, and two other leading world economies, Canada and the United Kingdom, make it apparent that FASD has a socioeconomic global impact. May et al. (2011) found that accurate estimates regarding the prevalence of FASD are lacking in western countries, and that the frequency of FASD may be higher in western countries than previously thought. May et al. did an epidemiology study in Italy where alcohol is consumed with meals and found that estimates were significantly higher than previously suggested, raising the question of whether FASD is more prevalent in western society than previously estimated. Yet, although knowledge about FASD has been far reaching, efforts to combat this problem are not coordinated internationally, such as the efforts to control disease through massive vaccinations in the interest of prevention of health problems.

The United States, by 1988, were spending four billion dollars annually on costs associated with FASD (Harwood, 2000, cited in Lupton, Burd, & Harwood, 2004). It is worthwhile noting that FASD is a preventable disability and the above expenditures could be applied to other social needs if the prevalence of FASD could be significantly reduced globally. Chuck Lupton, Substance Abuse and Mental Health Services Administration (SAMHSA), FASD Center for Excellence, advanced the thought of FASD as an economic concern. Lupton et al. (2004) listed several cost estimates regarding FASD, all of which were high, and concluded that at the very least the high costs associated with FASD easily justified extensive prevention efforts. For example, the lifetime cost of FASD in the US was estimated to be 596 thousand per person in 1980 (Harwood & Napolitano, 1985, cited in Lupton et al., 2004). Taking inflation into account, Lupton et al. predicted that as of 2002 the average lifetime cost per person with FASD would be approximately 2 million dollars.



Stade (2003) indicates that a conservative estimate suggests Canada alone spends over 340 million dollars annually to manage FASD. This estimate was limited to people diagnosed with FASD who fit into the category of 21 years of age or younger. The cost of FASD in Alberta is thought to be between 10 and 30 thousand dollars per person annually, with the family expected to pay 19 – 20% (Thanh & Johnson, 2009). Care plans that cost 2000-6000 dollars a year over the normal costs of raising children present a barrier for the potential adoption of children in care in jurisdictions in which adoptive parents are responsible for medical costs associated with the adopted child. Farris-Manning and Zandstra (2007) noted that “experts estimate 50% of the 6,600 kids in care in Alberta [1999] have FAS [Fetal Alcohol Syndrome]” (p.15). Each one of these children costs the taxpayer approximately 3 million dollars over the lifetime of the child (Jacobs, 1999, cited in Farris-Manning & Zandstra. Fuchs, Burnside, Marchenski, and Mudry (2007) who note the increasing amount of children with FASD coming into the Manitoba child welfare system, comment:

Because children with FASD enter the child welfare system at a younger age and spend a greater proportion of their lives in care than other children, their needs present an additional challenge to the child welfare system. The data on the increasing number of children coming into care and the prevalence data from the Addictions Foundation of Manitoba indicates an increasing degree of urgency for health, education and the child welfare systems to develop effective integrated health and service policy and programs to respond to the growing numbers of children and families with FASD (p.37).

The high costs associated with managing a child with FASD in state care and the increasing prevalence of children with FASD in state care, in provinces such as Alberta and Manitoba, suggest that FASD has become a critical issue in child welfare practice.

The above literature related to the financial costs of FASD focuses on total yearly government spending as well as yearly spending by people and families living with FASD. Figures pertaining to total overall national spending are arrived at, in a summative sense, by taking the estimated costs of a single instance of FASD, and multiplying that number by the estimated amount of people born with FASD yearly. Apparently missing from the literature are the personal accounts of the financial impacts of FASD from the very people that are living with the disorders. Moreover, it would be interesting to know if the financial costs associated with FASD are realistically affordable throughout the general population of North America. More research is needed around the financial burden of FASD on a personal and community level that encompasses the voice of people living with Fetal Alcohol Spectrum Disorder.

## Legal issues

In Canada, FASD is over represented in the criminal justice system (Fast & Conry, 2009). If the same is true of other countries, it could be concluded that people with FASD represent a diverse globally oppressed population, crossing all cultural, ethnic, as well as international boundaries. Given that alcohol is accessible and consumed during pregnancy, there will always be persons with FASD who, without interventions, may be incarcerated for actions caused by their disability (Fast & Conry). Fast and Conry advanced the research on FASD, indicating how it affects the legal system by reporting on FASD in the Canadian criminal justice system. They found the occurrence of persons with FASD in the criminal justice system appears to be far more significant than the estimated prevalence of 1-3% of the population (Fast et al., 1999, cited in Fast & Conry).

Fast and Conry (2009), in reviewing the criminal justice system and its effectiveness regarding housing people with FASD, came to the conclusion that the life-long neurological impairments found in people with FASD included “learning disabilities, impulsivity, hyperactivity and poor judgment, increase susceptibility to criminal behavior and victimization” (p. 256). Fast and Conry maintained that “offenders with FASD should not return to the community, after release, worse off than when they left, due to misunderstanding, victimization, and mismanagement of their disabilities” (p. 256). In order for the criminal justice system to properly accommodate FASD, Fast and Conry suggest that professionals should be subject to ongoing training regarding recognition and diagnosis of FASD as well as the ethical and cultural issues that arise in addressing the social and legal implications of FASD. It should be noted as a logical inference that increasing the judicial system’s ability to accommodate FASD must include increasing the understanding of why FASD is over represented in the criminal justice system, and subsequently, increase appropriate alternatives other than incarceration. Otherwise, the overrepresentation of FASD in the criminal justice system will not be addressed. To build this understanding, we need to go beyond surveys, straight to the narratives of inmates with FASD. Perhaps this way, we can gain insight into why people with FASD are at a higher risk of incarceration.

While the literature of the 1970s focused largely on the medical identification of FASD, the 1980s appeared to be the decade in the United States in which some US state legislatures slowly began to address, legally, the social issues associated with FAS. Ris (1988) reported that in 1985, 1987, and 1988, Wisconsin, Oregon, and Rhode Island, passed laws requiring information on FAS to be distributed with new marriage licenses. Efforts by these three states seemed to mark the beginning of state and thus, social involvement, in FAS prevention in the US. Ris indicated that no other US state, at the time the article was written, had successfully passed laws aimed at preventing FAS.

A further examination of laws pertaining to FAS and the state of Wisconsin indicated the Wisconsin legislature amended the state’s child protection laws by adding a FAS provision (De Ville & Kopelman, 1999). The change meant that Wisconsin judges could “confine pregnant women who abuse alcohol or drugs for the duration of their pregnancies” (De Ville & Kopelman, p. 332). In criticizing the law, De Ville and Kopelman wrote “Wisconsin’s fetal protection law collapses an issue involving individual maternal liberty into a revamped child abuse law, complicating the already intricate medical, moral, and social problem of substance use during pregnancy” (p.340). The law passed by the state of Wisconsin is significant as it supports a trend in child welfare in which some US states favored the protection of an unborn child over the liberty of the mother.

Bracken (2008) points out that the over-representation of Indigenous persons in the Canadian criminal justice system is also connected to discrimination, historical influences, and broader health and social development issues. Bracken suggests that FASD and the Canadian criminal justice “are often considered in the public mind as almost uniquely Aboriginal problems” (p. 26). Bracken points out that “this is a misconception born out of the percentages of aboriginal people involved in the criminal justice system in Canada” (p. 26). Similarly, Fast and Conry (2009) conclude FASD is overrepresented in the criminal system. The above accounts of Indigenous representation in Canadian criminal justice suggest FASD relates to the stereotyping of Indigenous people without concurrent analysis of FASD in White/Caucasian families as well as families in other backgrounds. Further research by Indigenous scholars is required to avoid potential discriminatory and stereotypical accounts by researchers from a dominant culture. Such research is essential in training human service workers to avoid thinking of the abuse of alcohol by a particular segment of the population, such as Indigenous people, in a stereotypical manner without the context in which it may occur.



## Cultural considerations

Culture is made up of norms, values, beliefs and ideals. The culture of the dominant group in society is presented as the universal cultural norm and suppresses or represses subordinate cultures (Mullaly, 2010). Mullaly suggests that when reflecting on another's behavior human service workers strive for cultural sensitivity by increasing their awareness of personal cultural influences in aiming to establish a helping relationship. Otherwise, human service workers can act in an oppressive manner by viewing a situation from a dominant group perspective, using its culture as the norm to analyze others (Mullaly). Mullaly explains that the tendency to apply a dominant group perspective to other cultures is so pervasive that the stereotyping that results is not questioned; for example, when black people are viewed as drug addicts and Indigenous people are seen as alcoholics. Thus, dominant group members fail to see the experience of the less dominant and "imposes on the oppressed group its experience and interpretation of social life" (Young, 1990, cited in Mullaly, p. 60).

Salmon (2011) explains how the dominant group in society fails to see how they oppress those who are less privileged. She suggests that in recent decades the Canadian government has increasingly focused and campaigned for the need to prevent FASD in Indigenous communities without sufficiently addressing systemic health inequities, such as poverty, racism and differential access to resources. Salmon (2011) points out that campaigns spearheaded by the Canadian government to promote the health of children, often use the same mediums of radio and print to educate the public on proper child care. Salmon notes that although radio and print media are expensive, using these methods to inform the public is far cheaper than addressing the root causes of systemic health inequalities, such as poverty. Salmon insists that campaigns to prevent FASD must be understood as emerging from a social, political and historical context. For example, Salmon writes about how the issue of patriarchy and mother blaming becomes more alarming in the context of Indigenous motherhood. Salmon discusses the conservative view that the health of a nation is the wealth of a nation, and therefore, women are responsible for producing healthy babies, and thus, are logically primarily responsible for a nation's general wealth. Salmon describes how Canada has a long history of emphasizing the female responsibility to have a healthy pregnancy and baby, "by avoiding alcohol, tobacco, and other drugs" (p. 168). Further, Salmon considers the impact of overrepresentation of Indigenous children with FASD in the Canadian child welfare system, suggesting it is a major factor in creating the stereotypical view of Indigenous mothers as "abusive, neglectful, and otherwise dangerous to their children" (Salmon, 2011, p. 169). Salmon describes this oppressive stereotyping as being the result of transferring white middleclass expectations of motherhood onto a, on average, far less affluent minority population by western standards (Salmon).

Tait (2003) states that less than one percent of the estimated populations believed to have FAS are diagnosed in Canada, pointing out that clinical, diagnostic inconsistency are common and that epidemiological evidence is inconclusive and/or methodologically questionable. However, Tait advises us that there is a sense of urgency in North America, leading to campaigns to stop all pregnant women from drinking alcohol. By drawing attention to the motivation behind the discourse, the grounds upon which it is legitimated and the implications it has on the lives of Indigenous women, Tait clearly supports the idea of the social construction of FAS.

Salmon (2011) reminds us that women who give birth to children with disabilities face stressful, caregiving responsibilities with limited social support, often finding it difficult to work and opting, out of necessity, to live on social assistance. Additionally, Salmon points out that Indigenous women may self-medicate with alcohol to contend with the trauma associated with the experience of residential schools, the removal of children from their care when they acknowledge a problem with substance abuse, and the lack of social, economic, political, and cultural opportunities.

Astley, Bailey, Talbot, and Claren (2000) contributed an important study in raising the issue of birth mothers and adding to the knowledge and deeper understanding of women's lives in relation to giving birth to children with FASD. Astley et al. suggest that the women most likely to have a child with FASD are unlikely to reduce their alcohol use on their own. They found that all 80 women in their study had addictions to alcohol that were connected to histories of severe physical, sexual and emotional abuse. Eight per cent reported living with violent males, unsupportive by any efforts to quit drinking during their pregnancy. Most of the women had endured isolation from community and family, poverty, and loss of previous children to child welfare agencies. These findings indicate that prevention programs that advertise the harmful effects of drinking alcohol while pregnant need to be coupled with other interventions. Thus, Canadian public health campaigns that simply suggest women stop drinking are inadequate and mainly serve to support stereotypical reaction that views mothers as solely responsible for a child born with FASD.

Research and the development of interventions have possibly been impeded by historical cynicism about researchers and workers. Specifically, it is conceivable that identifying the prevalence of FASD among Indigenous people may contribute to discrimination and oppression in ways that end up promoting misunderstandings about the incidence of FASD within Indigenous communities. In looking for ways to interact successfully with Indigenous communities, Masotti et al. (2006) suggest greater success can be accomplished by using a participatory action research (PAR) approach that involves concurrent collaboration between researchers and community members in the goal to create positive social action. PAR provides an option to develop interventions for FASD by capitalizing on the strengths of Indigenous communities by allowing community members to develop, implement and evaluate interventions, with researchers as collaborators in the documentation process.

The impact of colonial policies toward Indigenous people, and in particular the legacy of discrimination, forced assimilation and economic marginalization, must be considered when intervening and responding to Indigenous persons with FASD. The test for practitioners and policy makers is to develop ways of identifying FASD which does not perpetuate the stereotypes of Indigenous peoples.

## Implications for human service workers in child welfare

Although Gough and Fuchs (2006) indicate that there is a growing prevalence of FASD-Related disabilities, there does not appear to be a substantive knowledge base in the literature on child welfare practice in response to FASD. There is literature related to child welfare practice that is generally applicable to all children, including such topics as working with children with disabilities and benefits of cultural matching in foster care and adoption (Brown, George, Sintzel, & St. Arnault, 2009). However, Bohjanen, Humphrey, and Ryan (2009) undertook an extensive literature review that focused on

evidenced-based interventions intended for children and youth with FASD and found only three studies fit their criteria. Further, Premji, Serrett, Benzies, and Hayden (2004) reviewed literature for a similar purpose and found only ten studies which met their criteria. Although there is some literature pertaining to child welfare practice in response to FASD, it does not appear to be as substantive as, for example, medical-related literature. As children with FASD tend to enter the child welfare system at a younger age, and spend a greater proportion of their lives in care than other children (Fuchs, Burnside, Marchenski, & Mudry, 2007), human service workers need to prepare and become knowledgeable about the needs of children with FASD for whom they will inevitably provide service.

Fast and Conry (2009) note that although some training for human service workers who work with persons with FASD is happening, they insist there is a need for human service workers to have a greater understanding of the symptoms and interventions particularly relevant to FASD. For example, a certificate program is offered through Lethbridge College, to address a growing demand for support workers and caregivers to support children and adults with FASD, and for current professionals in various human service areas (Fetal Alcohol Spectrum Disorder Education, 2013).

Regulated, continuing professional curriculum about FASD is required for professionals involved in the criminal justice system. It is suggested that if professionals in the legal system can recognize FASD early, and are knowledgeable about the most appropriate interventions, the result may be a reduction in the overrepresentation of FASDs in the criminal justice system (Fast & Conry, 2009).

Fuchs et al. (2007) stress there is an immediate need for health, education and child welfare systems to develop and deliver integrated programs and services. For example, Alberta has a FASD 10-Year Strategic Plan which has resulted in the mobilization of local support networks. These support networks offer community-based coordinated assessment and diagnosis, targeted prevention, and support services for people affected by FASD and their caregivers. The implementation of the 10 year plan and the rise of local support networks is evidence the system is trying to respond to the social needs associated with FASD.

As a general rule, human service workers can justify a referral for a diagnostic assessment, for children, when characteristic symptoms of FASD are reported. Presently, there is no known solid system to diagnose adults. Potential indicators that an assessment is appropriate include a history of family alcohol problems, care providers other than the birth mother, attendance at special education classes, a previous diagnosis of attention deficit hyperactivity disorder, different home placements, suspensions from school, and friends from a different age group (Kellerman, 2005). When it is unknown if a child has been prenatally exposed to alcohol, concerns that may be visible or reports of concern by a parent or care provider may prompt a medical referral. Knowledge about FASD is critical for human service workers who work with children and youth who exhibit psychological/psychosocial and behavioral issues associated with FASD. These problems include trouble in school and with the law, cognitive and emotional issues, learning disabilities, alcohol and drug problems, memory problems, inappropriate sexual behaviors, poor organizational abilities, and focusing difficulties (Streissguth et al., 2004).

Initially, a knowledgeable worker may suspect FASD in a child client and refer the child for an assessment, creating the possibility of an early diagnosis and intervention. Once the diagnosis is obtained, human service workers knowledgeable about FASD can help monitor interventions to ensure children with FASD get the supportive assistance they need. Such a supportive environment would include sufficient structure in the home with in-home supports, if needed, and educational help with developing life skills by constructing the environment around the child's strengths.

Human service workers need to deliver services in a culturally sensitive manner as well as be cognizant of the medically-based needs of children in their care. Improving the quality of life, for the long term, for any person with a disability logically requires sufficient knowledge pertaining to the personal and social challenges the disabled person will face (Goodley, 2011; Meekosha & Dowse, 2007; Rothman, 2003). From a best practices perspective, human service workers who have knowledge of the historical, medical and social issues associated with FASD will be better prepared to provide appropriate interventions from a critically sensitive perspective. Workers knowledgeable and sensitive to cultural implications need to avoid unintentionally putting a birth mother in a position of being blameworthy, placing the mother at more risk of further psychosocial trauma.

Practically, human service workers can assist the family with a referral process to obtain a diagnosis and interventions by helping to educate the family on available services. They can offset the influence of the medical model with its emphasis on defining a problem and focusing on a cure with a social model that concentrates on social support for the person with FASD and their family. In child welfare, human service workers can dispel fears of apprehension by demonstrating they are present to help empower families with advocacy strategies in securing the required respite and supportive interventions needed. Extended family and friends can be included wherever and whenever possible in providing support and structure. Knowledge of FASD that is practical and focused on the needs for this population would be helpful. These measures help to initiate a pathway for success that is tailored with goals and objectives that meet a particular family's needs and abilities.

The education of human service workers should include knowledge of available supportive services and how to advocate for needed services (Fuchs, Burnside, Marchenski, & Murdy, 2010) as well as recognition of symptoms and knowledge about interventions. In supporting human service workers, there needs to be more research on the needs of children with FASD. More support for women struggling with addictions (Salmon, 2011) is needed to make it possible for parents to continue to be involved with their children and for children in the care of child welfare to return to their families of origin. Human service professionals should also play a role, along with persons with FASD and their caregiver, in developing policies for intervention and to further educate the public in preventing FASD and reducing stigma associated with FASD. In summary, exploring the history of FASD helps human service workers to see FASD as a complex issue that affects persons with FASD and their families medically, economically, legally, and socially, requiring knowledgeable workers who use appropriate interventions while exercising critically reflective practice.

## Conclusion

Most of the literature about FASD focuses on medical/scientific findings pertaining to prenatal alcohol exposure, important in ascertaining an early diagnosis and intervention (Gallicano, 2010). A review of the literature indicates how FASD expanded from largely medically-based research into economic, legal, and cultural considerations that required human service workers to exercise informed, critical, and reflective practice when intervening with persons with FASD. Medical knowledge and ongoing research about FASD is important but fails to connect to the social causes of FASD or suggest what knowledge and skills are beneficial to help those with an incurable chronic condition. The literature indicates that people with FASD need structure in their daily lives. However, the literature did not illustrate how human service workers should apply practice skills in helping persons with FASD and their families to create more structure in their daily routines to manage FASD; thus, highlighting a critical gap in published research in this area.

The literature also indicated concern about existing FASD prevention initiatives in Indigenous and other minority communities. Salmon (2011) suggests that FASD initiatives are designed for the majority in Canadian culture, and when applied to Indigenous communities, are more oppressive than helpful. For example, Salmon reports that if Indigenous women come forward requesting help regarding alcohol abuse, their children are often apprehended. Knowing that apprehension of their children may be the result of asking for help Indigenous mothers may very well refrain from asking for assistance (Astley et al., 2000).

More research regarding the social realities of FASD needs to happen, providing a knowledge base for intervention. Future research should focus on what works best with Indigenous families and communities with an emphasis on an Indigenous worldview and a methodology that uses a storytelling approach that provides feedback regarding more appropriate interventions. We need to move away from outcome-based research, such as surveys or risk assessment, to research that reflects the experience of the Indigenous community, such as narrative inquiry or participatory action research.

With appropriate knowledge and training we can effectively work to decrease the structural oppression evident in some of the interventions presently used. Clearly, FASD is a substantial issue that should garner adequate attention from training institutions. Human service workers trained on FASD, as well as other disabilities, will contribute to informed service for children with complex needs. Thus, it is essential post-secondary education prepare students in human service programs for their coming encounter with FASD with appropriate curriculum that is practical and culturally sensitive.

## References

- Alberta Human Services. (2012). *Fetal Alcohol Syndrome Disorder (FASD)*. Retrieved from <http://www.child.alberta.ca/home/594.cfm>
- Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000). Fetal alcohol syndrome (FAS) primary prevention through diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol and Alcoholism*, 35(5), 509-519.



- Bell, S. H., Stade, B., Reynolds, J. N., Rasmussen, C., Andrew, G., Hwang, P. A., & Carlen, P.L. (2010). The remarkably high prevalence of epilepsy and seizure history in fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 34(4), 1084-1089. doi:10.1111/j.15300277.2010.01184.x
- Bohjanen, S., Humphrey, M., & Ryan, S. M. (2009). Left behind: Lack of research-based interventions for children and youth with fetal alcohol spectrum disorders. *Rural Special Education Quarterly*, 28(2), 32-38.
- Bracken, D. C. (2008). Canada's Aboriginal people, Fetal Alcohol Syndrome & the criminal justice system. *British Journal of Community Justice*, 6(3), 21-33.
- Brown, J. D., George, N., Sintzel, J., St. Arnault, D. (2009). Benefits of cultural matching in foster care. *Children and Youth Services Review*, 31(9), 1019-1024.
- Chudley, A. E., Conry, J., Cook, J. L., Looock, C., Rosales, T., & LeBlanc, N. (2005). Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172: S1-S21.
- De Ville, K. A., & Kopelman, L. M. (1999). Fetal protection in Wisconsin's revised child abuse law: Right goal, wrong remedy. *Journal of Law, Medicine, & Ethics*, 27(4), 332-342.
- Drabble, L. A., Poole, N., Magri, R., Tumwesigye, N. M., Li, Q., & Plant, M. (2011). Conceiving risk, divergent responses: Perspectives on the construction of risk of FASD in six countries. *Substance Use Misuse*, 46(8), 943-958. doi:10.3109/10826084.2010.527419
- Farris-Manning, C., & Zandstra, M. (2007). Children in care in Canada. Canada: Child welfare League. Retrieved from [http://www.nationalchildrensalliance.com/nca/pubs/2003/Children\\_in\\_Care\\_March\\_2003.pdf](http://www.nationalchildrensalliance.com/nca/pubs/2003/Children_in_Care_March_2003.pdf)
- Fast, D. K., & Conry, J. (2009). Fetal alcohol spectrum disorders and the criminal justice system. *Developmental Disability Research Reviews*, 15(3), 250-7.
- Fast, D. K., Conry, J. L., & Looock, C.A. (1999). Identifying fetal alcohol syndrome (FAS) among youth in the criminal justice system. *Journal of Developmental & Behavioral Pediatrics*, 20(5), 370-372.
- Fetal Alcohol Spectrum Disorder Education. Lethbridge College. (2013). Retrieved from <http://www.lethbridgecollege.ca/program/fasd>
- Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2007). Children with FASD: Involved with the Manitoba child welfare system. Retrieved from <http://www.cecw-cepb.ca/node/591>
- Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2010). Children with FASD-Related disabilities receiving services from child welfare agencies in Manitoba. *International Journal of Mental Health Addiction*, 8(2), 232-244. doi 10.1007/s11469-009-9258-5.
- Gabriel, K., Hofmann, C., Glavas, M., & Weinberg, J. (1998). The hormonal effects of alcohol use on the mother and fetus. *Alcohol Health & Research World*, 22(3), 170-177.
- Gallicano, G. I. (2010). Alcohol and its effect on fetal development: What do we know? *Pediatric Health*, 4(5), 459-62.



- Goodley, D (2011). *Disability studies: An interdisciplinary introduction*. California, CA: Sage Publications Ltd.
- Gough, P., & Fuchs, D. (2006). Children with FASD-related disabilities receiving services from child welfare agencies in Manitoba. Toronto, ON: Centre of Excellence for Child Welfare. Retrieved from: <http://www.cwrp.ca/publications/430>
- Harwood, H. (2000). Updating estimates of the economic costs of alcohol abuse in the United States: estimates, update methods and data. Report prepared by the Lewin Group. Bethesda, MD: National Institute on Alcohol Abuse and Alcoholism.
- Harwood, H. J., & Napolitano, D. M. (1985). Economic implications of the fetal alcohol syndrome. *Alcohol Health & Research World*, 10(1):38-43; 74-75.
- Jacobs M. (1999, September 2). Is there no way to get FAS relief? The Edmonton Sun.
- Jones, K. L., & Smith, D.W. (1973). Recognition of the fetal alcohol syndrome in early infancy. *The Lancet*, 2(836), 999-1001.
- Kalberg, W. O., & Buckley, D. (2007). FASD: What types of intervention and rehabilitation are useful? *Neuroscience & Biobehavioral Reviews*, 31(2), 278- 285. doi:10.1016/j.neubiorev.2006.06.014
- Kellerman, T. (2005). Recommended Assessment Tools for Children and Adults with Confirmed Or Suspected FASD. Retrieved from <http://comeover.to/FAS/AssessmentsFASD.htm>
- Lethbridge College (2012). Programs and courses. Fetal Alcohol Syndrome disorder. Retrieved from <http://www.lethbridgecollege.ca/program/fasd>
- Levine, H. G. (1983). The good creature of god and the demon rum. In National Institute on Alcohol Abuse and Alcoholism (pp. 111-161), *Research Monograph No. 12: Alcohol and disinhibition: Nature and meaning of the link*, NIAAA, Rockville, MD, p. 115.
- Lupton, C., Burd, L., & Harwood, R. (2004). Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics*, 127(1), 42– 50.
- Masotti, P., George, M. A., Szala-Meneok, K., Morton, A. M., Looock, C., Van Bibber, M., Ranford, J., Fleming, M., & MacLeod, S. (2006). *Preventing fetal alcohol spectrum disorder in Aboriginal Communities: A methods development project*. *PLOS Medicine*, 3(1): e8.
- May, P. A., Fiorentino, D., Coriale, G., Kalberg, W. O., Hoyme, H. E., Aragon, A. S., Buckley, D., Stellavato, C., Gossage, J. P., Robinson, L. K., Jones, K. L., Manning, M., & Ceccanti, M. (2011). Prevalence of children with severe fetal alcohol spectrum disorders in communities near Rome, Italy: New estimated rates are higher than previous estimates. *International Journal of Environmental Research and Public Health*, 8(6), 2331-2351.
- Meekosha, H. & Dowse, L. (2007). Integrating critical disability studies into social work education and practice: An Australian perspective. *Practice*, 19(3), 169-183.
- Mullaly, B. (2010). Forms of oppression. Chapter 2. Oppression: An overview. *Challenging oppression and confronting privilege* (2<sup>nd</sup>.Ed.) (pp. 55-61). Toronto: ON: Oxford University Press.

- Premji, S., Serrett, K., Benzies, K., & Hayden, K. A. (2004). *The state of the evidence review: Interventions for children and youth with a fetal alcohol spectrum disorder (FASD)*. Calgary, AB: Alberta Centre for Child, Family & Community Research.
- Ris, H. W. (1988). Fetal alcohol syndrome: legislation urgently needed. *Journal of Public Health Policy*, 9(4), 556-558.
- Rothman, J. (2003). *Social work practice across disability*. Boston: Allyn & Bacon.
- Root, A. W., Reiter, E. O., Andriola, M., & Duckett, G. (1975). Hypothalamic-pituitary function in the fetal alcohol syndrome. *The Journal of Pediatrics*, 87(4), 585-588.  
doi:10.1016/S00223476(75)808304
- Salmon, A. (2011). Aboriginal mothering, FASD prevention and the contestations of neoliberal citizenship. *Critical Public Health*, 21(2), 165-178.
- Stade, B. C. (2003). *The burden of prenatal exposure to alcohol: Measurement of quality of life and costs*. (Doctoral dissertation). University of Toronto (Canada). Available from ProQuest Dissertations and Theses database.
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K. M., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics*, 25(4), 228-238.
- Strömmland, K. (1987). Ocular involvement in the fetal alcohol syndrome. *Survey of Ophthalmology*, 31(4), 277-284. doi:10.1016/0039-6257(87)90028-2
- Tellez-Zenteno, J. F., Pondal-Sordo, M., Matijevic, S., & Wiebe, S. (2004). National and regional prevalence of self-reported epilepsy in Canada. *Epilepsia*, 45, 1623-1629.
- Tait, C. (2003). *The tip of the iceberg: The Making of fetal alcohol syndrome in Canada*. Unpublished doctoral dissertation. McGill University, Montreal, PQ, Canada.
- Thanh, N. X., & Johnson, E. (2009). Costs of fetal alcohol spectrum disorder in Alberta, Canada. *Canadian Journal of Clinical Pharmacology*, 16(1), 80-90.
- Young, I. M. (1990). *Justice and the politics of difference*. Princeton, NJ: Princeton University Press.