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# Inventory of Literature on the Assessment and Diagnosis of **FASD Among Adults**

A National and International Systematic Review

Canada

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## Executive summary

The scope of this project was to discover and review the existing literature in relation to adult diagnosis of Fetal Alcohol Spectrum Disorder (FASD). This is a developing field where, although the primary focus has been on the diagnosis of children, in recent years there has been an increasing emphasis on adult and adolescent assessment and diagnosis. Since the initial concern of Fetal Alcohol Syndrome (FAS) was raised in the literature in 1973 by Jones, Smith, Ulleland & Streissguth, and Lemoine, Harousseau, Borteyru & Menuet (1968), scientific research and practice responses have emerged from a wide variety of disciplines. One of the points emphasized by Stratton, Howe & Battaglia (1996) when the Institute of Medicine published its guidelines for diagnosis of FASD was that multiple disciplines were required to respond to this issue. However, social science research has not kept pace with biomedical research. Leadership on FASD research has clearly emerged from the discipline of medicine (Jones et al., 1973) and was initially related to the biological complexity of disorders related to alcohol exposure in utero. The psychosocial implications of a diagnosis of FAS/FASD emerged over time, often through insistent concerns raised by parents, foster parents and members of professions such as psychology, social work, community rehabilitation, nursing and justice. Since the diagnosis has been maintained within a medical paradigm, the leading research emerged from this discipline. Canadian researchers have developed Canadian Guidelines for Diagnosis (Chudley et al., 2005). While the physical etiology of FAS/FASD was well documented, the social etiology slowly unfolded as awareness grew of the profound impact of alcohol exposure on human development. In particular, Streissguth (1997) was a pivotal researcher in bringing awareness to the psychosocial issues related to a diagnosis of FAS (Streissguth, 1997; Streissguth & Kanter, 1997) and FASD (Streissguth & O'Malley, 2000).

Alcohol-exposed individuals, both children and adults, have specific concerns that require assessment leading to diagnosis, and subsequently, a treatment plan based on individual strengths, problems and needs. Although it is widely recognized that it is important to diagnose children, the same concern exists for adults. Awareness of FASD has grown within the medical and helping professions due to ongoing training initiatives with leadership from organizations such as the Canada Northwest FASD Partnership and Research Network, the Atlantic Intergovernmental FASD Partnership, the FASD Intergovernmental Action Network for Ontario, and individual provinces such as Quebec. In terms of addressing educational needs related to FASD, there is an annual Alberta FASD conference and the University of British Columbia's Continuing Education holds annual conferences in collaboration with the B.C. Centre of Excellence for Women's Health. As awareness of FASD has grown across Canada and internationally, educational opportunities have increased and the Canadian Centre for Substance Abuse has identified an inventory of trainers.<sup>1</sup> The strategic plan of the FASD Cross-Ministry Committee in Alberta focused on highlights for practice, while the University of British Columbia's Continuing Education holds annual conferences in collaboration with the B.C. Centre of Excellence for Women's Health and the Alberta Fetal Alcohol Network. Additionally, the Public Health Agency of Canada has funded a number of



strategically directed research initiatives related to Indian and Northern Affairs Canada, Justice Canada and Youth Justice Policy, and Public Safety Canada. It is recognized that this is not an exhaustive list as many awareness, training and intervention initiatives have evolved over the years.

The need to diagnose adults has emerged from multiple sectors (e.g. health, justice, housing, education, social services). The understanding of the need to support families through identification of FASD in both children and adults will promote healthier families and communities.

In taking up this review of the available research literature on FASD, it was clear that research is emerging that focuses on adults (e.g. Barr et al., 2006; Boland, Chudley & Grant, 2002; Bookstein, Streissguth, Sampson, Connor & Barr, 2002; Camden & Spiegel, 2007; Chudley, Kilgour, Cranston & Edwards, 2007; Clark et al., 2008; Connor, Sampson, Streissguth, Bookstein & Barr, 2006; Duquette, Stodel, Fullarton & Hagglund et al., 2006; Fagerlund et al., 2006; Famy, Streissguth & Unis, 1998; Kerns, Don, Mateer & Streissguth, 1997; Rudnick & Ornoy, 1999; Spear & Molina, 2005; Spohr, Willms & Steinhausen, 2007; Streissguth, 1994; Streissguth, Sampson & Barr, 1989; Sullivan, 2008; Yates, Cadoret, Troughton, Stewart & Giunta, 1998). This emerging knowledge raises concerns about the need to offer these individuals the opportunity for diagnosis. This same research highlights some of the challenges faced in assessing adults. Many individuals are diagnosing themselves based on personal family histories related to alcohol use during pregnancy, while others are being referred for assessment by various social, health care and mental health professions. An area that has not been explored in the literature is the social consequences of self-diagnosis.

The process of searching, locating and evaluating the existing literature in relation to adult diagnosis has been refreshing. It presented an opportunity to engage in a focused process that truly highlights the need for a standardized approach and response to alcohol-exposed adults. This literature review has provided a venue for understanding and support, important for a brighter future for individuals and their families/support system for moving forward cognizant of the particular needs arising from FASD.

The key areas in this report include an introduction, literature review methodology, and a literature review of adult diagnosis and assessment, implications and conclusions. We focused on both Canadian and international literature, using the following process:

- 1. Conduct a systematic search and assembly of Canadian and select international, empirical and qualitative literature and data on the assessment and diagnosis of adults for the impact of in utero exposure to alcohol.**
- 2. Create a synthesis and critical review of the information obtained, including the identification of strengths, limitations and gaps.**
- 3. Prepare recommendations of next steps for areas of further research.**

1 [www.ccsa.ca/Eng/KnowledgeCentre/OurDatabases/FASD/Pages/default.aspx](http://www.ccsa.ca/Eng/KnowledgeCentre/OurDatabases/FASD/Pages/default.aspx)



This process yielded information that was impressive because of the short time frame associated with this project. Clarren and Lutke (2008) reported that there are at least 27 clinics in Western and Northern Canada engaged in diagnostic activity related to FASD, with a few of these facilitating or specializing in adult diagnosis. In contextualizing adult diagnosis, the critical issue of the problematic misuse of alcohol was highlighted. This remains a core issue requiring targeted efforts at treatment and long-term support, particularly for women who are at risk, or have previously given birth to, a child with FASD. Further, concerns for the partners of women who are the biological fathers must be addressed, as there is a paucity of literature on this topic. Considering that FASD emerged in the literature 40 years ago in France (1968) and in 1973 in North America, progress on responding to this issue has been both remarkable and substantial – due to the efforts of dedicated physicians, families and professionals who support positive outcomes for alcohol-exposed children and adults. As the children who have been diagnosed over the past decades grow up, they have paved the way to deepening our understanding of their needs and challenge us to develop models of excellence in response to assist them in negotiating the world around them. Many of those concerned have stepped up to the challenge by consistently making efforts to develop models of excellence in the diagnosis of FASD, including adult diagnosis.

The Canadian model for diagnosis has drawn on both the U.S. Institute of Medicine (1996) as cited in Hoyme et al. (2005) and the Diagnostic Prevention Network 4-Digit Diagnostic Code developed by Astley and Clarren (1999). It is described in greater detail in this report. The Canadian guidelines retained the standards of the 4-Digit Diagnostic Code and the spectrum terminology of FASD from the U.S. Institute of Medicine (IOM) model.

One of the concerns that arises in diagnosis is the differential use of terminology internationally. There remains an inconsistent understanding of diagnostic terminology outside of the medical professions, as the focus of health and social service professionals lies outside of these parameters. A basic understanding of FASD exists, but a model for understanding the intricacies and implications of this diagnosis in day-to-day living for diagnosed persons is not coherent in practice. Inconsistencies also arise in the work of medical professionals in relation to diagnostic protocols, and a lack of clinics for adults leads to greater concern about standards of practice and consistency in diagnosis in Canada.

More recently, Sullivan (2008) focused on underlying vulnerabilities and problems in life adaptations, including “poor parental role modeling, disturbed development of trust and identity, patterns of avoidant coping behaviour, dysfunctional adolescent and adult relationships, and economic disadvantage” (p. 226). These concerns are realities for adults with the disorder and indeed pose challenges as intervention aimed at ameliorating these concerns is time-intensive and costly. A small literature is beginning to appear that focuses on the quality of life of individuals living with FASD, which may provide a fuller picture of what it means to live with FASD and how we can improve the quality of life for these children, adolescents and adults (Grant, Huggins, Connor & Streissguth, 2005; Stade, Stevens, Ungar, Beyene & Koren, 2006).



Since FASD has been identified as a health concern in Canada and other countries, the need to address the issue across the lifespan falls within the practice framework of health, social services and the community. Although FASD does not fit neatly into the adult world of developmental disability due to many of the inherent social problems and neurobehavioural problems associated with this diagnosis, consultation in relation to working with systems and supports for adults with disabilities can inform the development of service models.

### **Conclusions and Implications**

The response to adult diagnosis has evolved but has been fragmented without a consistent framework in which to house diagnostic services. It is clear from this review that adult diagnostic resources are sparse, yet slowly evolving. We see examples such as the Lakeland Centre for FASD, the Asante Centre, the OBD Triage Institute (pre-screening for diagnostic referral), the FASD Community Circle and the Adult Assessment and Diagnostic Project in Western Canada. The only resource identified in Eastern Canada related to diagnosis of adults was located at St. Michael's Hospital in Toronto. Motherisk, under the direction of Dr. Gideon Koren and colleagues, has been a leading resource in relation to the diagnosis of children and in the development of the *International Journal of Fetal Alcohol Syndrome* (now entitled the *Canadian Journal of Clinical Pharmacology Incorporating Fetal Alcohol Research*). Canada does have a research network known as FACE (Fetal Alcohol Canadian Expertise), which has been offering research roundtables since 2000. FACE partners include Health Canada's First Nations and Inuit Health Branch, Public Health Agency of Canada, Government of Alberta, Government of British Columbia, the Brewers Association of Canada, and Motherisk. A systematic approach to adult diagnosis is not yet developed in Canada.

Canada, however, has demonstrated remarkable leadership in responding to the issue of FASD. The establishment of clinics for children should lead to the establishment of clinics for adults that are publicly funded in order to support individuals who do not have the resources to obtain a diagnosis on a fee-for-service basis. The potential exists for the costs of screening and assessment to put a fiscal strain on community-based agencies. However, publicly funded diagnosis is not consistently applied on a federal basis and discrepancies in the delivery of this service both in policy and practice should be addressed.





Referrals for adults would have to be restructured from the processes for children and strong screening protocols established for referrals to adult clinics. The potential for self-referral by adults is likely, as many may not be connected to agencies that might facilitate a screening/diagnostic referral. Following already established referral/screening/diagnostic protocols for children with some adjustments for adults would save time and fiscal resources in the development of adult clinics. As well, consultation with already established adult diagnostic resources would be useful to gain knowledge about their procedures and protocols.

Clearly, the need exists to respond to this issue, and the professional body of practitioners, family members and caregivers who support alcohol-exposed adults would benefit from diagnosis and follow-up services. However, the recognition of the desire and need for adult diagnosis raises concern about post-diagnosis. Does the infrastructure exist to offer follow-up services? How will this concern be addressed? This leads to the question of what a model of lifelong support looks like and raises another challenge in terms of response. Given that considerable expertise and support responses have been developed in relation to children, it is hoped that such expertise could extend to adulthood.

Another area that is important to consider is the development of case practice scenarios and models to develop a stronger knowledge base about referrals for screening/diagnosis for FASD in adults. Families, both foster and adoptive, have primarily raised their voices in relation to the needs of their FASD-diagnosed children as they made the transitions to adulthood. Concerns abound in the child welfare system that children will “age-out” of established supports and be left floundering as adults without an adequate support system, relying primarily on informal rather than formal services. Again, the knowledge that FASD is a lifelong disability raises a moral imperative about the provision of services post-diagnosis across the lifespan.

From a human rights perspective, it is critical to consider that the individual who has been diagnosed has a disability that in theory is preventable. However, the reality is that exigent circumstances exist that lead to the birth of children with FASD, including the possibility that mothers themselves may have been alcohol exposed and subject to intergenerational alcoholism, abuse and neglect. The argument of prevention presents a challenge when the lives of birth mothers are critically examined (Badry, 2008; Poole, 2003; Rutman, Callahan, Lundquist, Jackson & Field, 2000). Justice Canada has highlighted this issue and suggests that concerns exist from a human rights perspective due to the vulnerability of persons with FASD in society, including the risks of poverty, homelessness and conflict with the law. The implications of FASD from a human rights perspective requires further exploration.

# 1.0 Introduction

■ The cornerstone of responding to Fetal Alcohol Spectrum Disorder (FASD) is assessment and diagnosis. Medical, psychological, occupational therapy, speech and language pathology assessments, along with a detailed social history are critical components of the assessment process for FASD. Sensitive guidelines have been developed to support the diagnostic process. These include the Canadian Guidelines for Diagnosis (Chudley et al., 2005), 4-Digit Diagnostic Code (Astley & Clarren, 1999) and the U.S. Institute of Medicine guidelines (Institute of Medicine, 1996, as cited in Hoyme et al., 2005). The term “Fetal Alcohol Syndrome” (FAS) is primarily used in literature that predates 2000 (Jones, Smith, Ulleland & Streissguth, 1973), while literature post-2000 often refers to the term “FASD” (Streissguth & O’Malley, 2000).

Chudley, Kilgour, Cranston and Edwards (2007) described the wide range of features characterized by the various diagnoses within the spectrum of FASD diagnoses as those diagnosed with FAS at one end and those with behavioural and cognitive deficits who may have minimal or no physical characteristics but who have sustained brain injury due to in utero alcohol exposure at the other end. The diagnostic terms encompassed by FASD as per the published recommendations of the U.S. Institute of Medicine in 1996 include FAS (Jones, Smith, Ulleland & Streissguth, 1973), Partial FAS (pFAS), which was previously referred to in the literature as Fetal Alcohol Effects (FAE) (Streissguth et al., 1991; Streissguth, Barr, Kogan & Bookstein, 1997)

and a more recent addition to the terminology – Alcohol Related Neurodevelopmental Disorder (ARND) (Sampson et al., 1997; Stratton, Howe & Battaglia, 1996) and Alcohol-Related Birth Defects (ARBD). It was recommended by medical experts Aase, Jones and Clarren (1995) that FAE not be used due to negative interpretations and misconceptions related to this term, particularly regarding the issue that fetal alcohol exposure was the sole cause of problems for the individual. The 4-Digit Diagnostic Code does not use ARND and indicates that “static encephalopathy” is a term that is used to reflect more severe neurodevelopmental problems, while the term “neurobehavioural disorder” reflects a milder problem (Astley, 2006).



## 1.1

### Project Scope

The purpose of this project is to provide an overview of the existing Canadian and international literature on techniques and best practices for the diagnosis and assessment of adults for the impact of in utero exposure to alcohol. The parameters were as follows:

- 1. Conduct a systematic search and assembly of Canadian and select international, empirical and qualitative literature and data on the assessment and diagnosis of adults for the impact of in utero exposure to alcohol.**
- 2. Create a synthesis and critical review of the information obtained, including the identification of strengths, limitations and gaps.**
- 3. Prepare recommendations of next steps for areas of further research.**

## 1.2

### Adult Diagnosis in Context

At the root of the social problems associated with FASD is the problematic use of alcohol. The Alberta government, through the Alberta Alcohol and Drug Abuse Commission (AADAC), offers multiple counselling and treatment programs for people struggling with abuse of both alcohol and drugs. On November 18, 2008, the Canadian Executive Council on Addictions, the Canadian Centre on Substance Abuse, Centre for Addiction and Mental Health and BC Mental Health & Addiction Services announced the development of a new strategic initiative focused on a national treatment strategy for those with substance use problems. This research group indicates that the cost of substance abuse in Canada is close to \$40 billion annually and raises concerns about the lack of a national strategy. In the interest of prevention of FASD, a consistent approach to the problematic use of alcohol within society is critical. Due to the diversity of programs across Canada, this group recommends a “Tiered Model of Services and Supports” that recognizes “acuity, chronicity and complexity of substance use risks and harms, and their corresponding intensity.”<sup>2</sup> This report is raising a critical discourse on the need to address issues of consistency relevant to approaches to substance use treatment from a national perspective.

2 [www.nationalframework-cadrenational.ca/uploads/files/TWS\\_Treatment/generic-nts-presentation-eng.ppt](http://www.nationalframework-cadrenational.ca/uploads/files/TWS_Treatment/generic-nts-presentation-eng.ppt)



In 2008, AADAC programs were rolled into existing programs under the auspices of Alberta Health, but future directions were still unknown at the time of writing. The Canadian Executive Council on Addiction, the Canadian Centre on Substance Abuse (CCSA) and Health Canada released a report in 2004 called the Canadian Addiction Survey (cited in Alberta Alcohol and Drug Abuse Commission, 2006). The report's focus was on the alcohol and drug use of Canadians over the age of 15, and reported that

▶ **“17% (13.6% of all Canadians) are considered high risk drinkers .... The proportion of women drinkers identified as high risk are 8.9% and of men 25.1%”**

(p. 4). Alberta ranked as one of the five highest provinces in terms of overall lifetime alcohol use. This is a substantial problem and affects many people, as alcohol is an integral part of the socialization processes in society. Key harms identified by CCSA and Health Canada due to alcohol use were in relation to physical health over the lifetime (11.6%), social life (10.5%), followed in descending order by home life, work and finances. This survey offered a profile of the problems associated with alcohol consumption and brought attention to concerns about the use of alcohol in Canadian society and the perceived consequences of the problems associated with its use.

The concept of FAS had its origins in the early 1960s. An article entitled *The children of alcoholic mothers, observed anomalies,*

*discussion of 127 cases*, was published in the French Archives of Paediatrics by pediatrician, Dr. Paul Lemoine in 1968. Lemoine (2003) stated:

**Around 1960, two French studies independently proved for the first time the true dangers of alcohol use in pregnant women. The first was Jaqueline Rouquette's thesis entitled “Influences of the parental alcoholic intoxication on the physical and psychological development of young children” [written in Paris, France, 1957]. This work directly involved the study of children of alcoholics.... She observed effects on the children, especially with maternal alcoholism, and she presented a clear description of alcoholic fetopathies, as they are known today. This thesis appears to have been ignored – a fact that surprised me when I later discovered it while preparing a bibliography.**

**The second study, by me [Lemoine], started with no pre-conceived thoughts about alcoholism. It was while researching the cause of a strange dystrophy seen in certain children that I discovered alcoholism in their mothers.... Around 1960, I was struck by the existence of a yet unknown syndrome among these children... the children all looked as if they were siblings.... I was comparing two of these children looking for an answer, and while talking to the staff as I always did, one of them responsible for the two children indicated to me that both of their mothers were heavily alcohol dependent.... All of the children marked by this syndrome had alcoholic mothers. (Lemoine, 2003, p. 2)**



Lemoine described a methodology in which he both physically observed children in his practice as a pediatrician and subsequently did file reviews of each case. However, the genesis of the terminology FAS did not spring from Lemoine's work in 1960 as one would expect. Lemoine (2003) had used the term "alcoholic fetopathies," which he indicated meant the same as the North American term "FAS."

The term "Fetal Alcohol Syndrome" (FAS) came from the discovery of facial and physical anomalies by a specialized field of study in medicine called dysmorphology. The first article published in North America in *The Lancet* was entitled "Pattern of malformation in offspring of chronic alcoholic mothers" (Jones, Smith, Ulleland & Streissguth, 1973, p. 1). The findings of this article are highlighted:

**Eight unrelated children of three different ethnic groups, all born to mothers who were chronic alcoholics, have a similar pattern of craniofacial, limb, and cardiovascular defects associated with prenatal-onset growth deficiency and developmental delay. This seems to be the first reported association between maternal alcoholism and aberrant morphogenesis in the offspring.... Eight children born of alcoholic mothers were brought together and evaluated at the same time by the same observers (K.J. and D.W.S.). Four of these children were recognised as having a similar pattern of altered growth and morphogenesis. Thereafter, two other children were ascertained by the abnormal features**

**identified in the first four patients, while the remaining two affected children were ascertained because their mothers were chronically alcoholic.... All drank excessively throughout the pregnancy, the mothers of patients 1 and 7 to the extent that they were in hospital with delirium tremens. Patient 3 was born while her mother was in an alcoholic stupor. None of the mothers was known to be addicted to any other drug. (Jones, Smith, Ulleland & Streissguth, 1973, pp. 1267–1271)**

Streissguth (1994), in her review of the first decade of research into FAS, highlighted the international nature of the studies citing Lemoine, Harousseau, Borteyru and Menuet in 1968 and Dehaene et al. in 1977 emerging from France; German contributions by Majewski et al. in 1976; from Sweden the research by Olegard et al. in 1979; and research surfacing from the United States by Jones, Smith, Ulleland and Streissguth (1973). Research across the intervening decades, although dominated by North America, has continued to arouse interests from other countries (e.g. Riley et al., 2003 presented six international perspectives on the neurobehavioural consequences of fetal alcohol exposure in South Africa, the United States, Russia and Finland). Another indicator of international research is the studies comparing findings from multiple countries, such as those of Peadon, Fremantle, Bower and Elliott (2008) who sent questionnaires to diagnostic clinics in Canada, the United States, Chile, South Africa, Italy and the United Kingdom; and Moore et al. (2007), who included in their sample 276



subjects from three international sites (i.e. South Africa, Finland and the United States). A report on the proceedings of a workshop held in Japan in 2000 acknowledges research contributions from the United States, South Africa, Japan, Russia and Germany (Warren et al., 2001).

Since FAS was identified in the medical research literature only in 1973, it took a number of years for this information to filter out to social services, community health, physicians and allied professionals that may have come into contact with individuals with FAS/FASD and the publications were primarily medical in origin. It is believed that many individuals with disabilities related to fetal alcohol exposure were served in the developmental disability field and mental health, as diagnostic clinics had not yet been established outside of the early seminal work at the University of Seattle, Washington. Many individuals were served in the disability field with disabilities of unknown origin. In retrospect, with what we now know about FASD, it is likely that service provision occurred through this system. For example, from one author's work in the field of child welfare between 1986 and 2002, she encountered both children and adults where it was known their disabilities were caused by fetal alcohol exposure. The family of origin's social histories indicated serious problems with alcoholism that led to their contact with the child welfare system (Badry, 2008).

The 1980s brought the emergence of concerns regarding adolescent and adult development vis-à-vis diagnosed FASD, and the consideration of FASD across the lifespan. The reluctance to make initial diagnoses in these age groups was overcome with the publication of 10-year follow-up studies in the United States, France and Germany. Streissguth (1994) commented on the findings of these studies, which focused on the long-term central nervous system (CNS) involvement:

► **“The decreasing specificity of the face and growth deficiency after puberty only explains why initial identification of people with FAS after puberty can be more difficult.**

In FAS, the physical features are only the markers for the CNS deficits.... Although the physical features associated with FAS may change in adolescence, the CNS problems continue, often with more severe repercussions than those experienced in early childhood” (p. 75). Adaptive living deficits resulting from CNS deficits meant that those with IQs in the low normal range seemed “headed for trouble in the community” (p. 76). This finding has been supported by other research studies (e.g. Clark, Minnes, Lutke & Ouellette-Kuntz, 2008; Dyer, Alberts & Neimann, 1997; Grant, Huggins, Connor & Streissguth, 2005; Kerns, Don, Mateer & Streissguth, 1997) as well as the practice literature.



Knowledge about FASD has grown and evolved with each passing decade. The 1990s saw the emergence of a new phase of diagnostic development. There appeared to be two different schools of thought in the United States in terms of diagnosis based on standards set by the U.S. Institute of Medicine (Stratton, Howe & Battaglia, 1996) and the 4-Digit Diagnostic Code (Astley & Clarren, 1999). Diagnosis relies heavily on classification systems, which provide a portrait of the characteristics that constitute a particular condition or disease. A Canadian model for diagnosis has drawn on both the U.S. Institute of Medicine (1996, as cited in Hoyme et al., 2005) literature and the Diagnostic Prevention Network 4-Digit Diagnostic Code developed by Astley & Clarren (1999). The Canadian guidelines retained the standards of the 4-Digit Diagnostic Code and the spectrum terminology of FASD from the U.S. Institute of Medicine (IOM) model. The Canadian guidelines for a diagnosis of FAS include: “evidence of prenatal growth impairment [related to weight and height], simultaneous presentation of 3 [particular] facial features, evidence of impairment in 3 [particular] ... central nervous domains [and] confirmed (or unconfirmed) maternal alcohol exposure” (Chudley et al., 2005, pp. s11–s12).

Another trend in the closing years of the past century was a focus on identifying and raising awareness of the secondary conditions that are likely to arise as persons with FASD age. These conditions are a consequence of the primary disabilities related to CNS abnormalities.

The pivotal work of Streissguth, Barr, Kogan & Bookstein (1997) suggested that diagnosis before age six is a mediating factor against the development of serious social problems, which she identified as secondary disabilities. There is agreement among professionals who work with those living with alcohol-related disabilities that diagnosis is important to develop support plans that will assist individuals in negotiating home, educational, social and community environments. Although significant resources have been designated in the interest of diagnosing children suspected to have FASD, similar resources do not exist for adults. The purpose of this review was to determine what exists in both academic and grey literature that is relevant to the issue of adult diagnosis of FASD.

FASD research and clinical practice in the early 2000s are focusing on seeking more reliable prevalence rates, the diagnosis of adults, and intervention for children, adolescents and adults in the post-diagnosis period and across the lifespan. For example, in a study of current research on interventions related to FASD, Premji, Benzies, Serrett and Hayden (2007) suggested that there is little research available to guide interventions for children and youth (this is even more so with adults). This study highlights that supports for children living with disabilities as a result of fetal alcohol exposure are not yet developed. Real prevalence rates do not exist and are not tracked on any single database, so there is no overall profile of persons with FAS/FASD in



Canada. Premji and colleagues have identified a lack of intervention literature for children and the same problem exists in the adult world.

Hutson (2006) estimated that

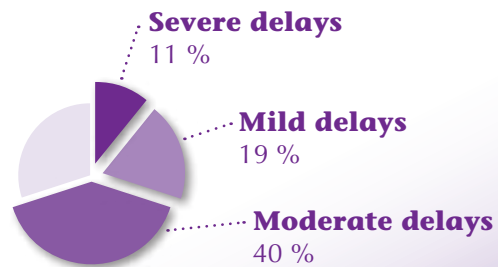
▶ **“3000 babies are born with FASD in Canada”**

every year and cited a report from Farris-Manning and Zandstra (2003) which further estimates “that 50% of children in care in Alberta have FAS” (p. 2). Alberta Health Services suggested that it is estimated that 9 of every 1,000 births have an FASD. Fuchs, Burnside, Marchenski and Mudry (2005), in their research of children in the care of child welfare agencies in Manitoba, estimated that 17% of children in care have an FASD. Variance among prevalence rates exists, as there is no coordinated approach to gathering this information in Canada.

Concerns about alcohol use and pregnancy have been raised as emerging concerns in other countries (e.g. alcohol use during pregnancy in Russia is a serious problem, which the West recently became more aware of, due to international adoptions of children from orphanages into Canada, the United States and other countries). One study by Miller et al. (2006) examined an orphanage in Russia, and considered the use of alcohol within this society. “Alcohol use in Russia is staggering; the annual consumption is among the highest in the world” (p. 532). Miller and colleagues estimated that 58% of children (n = 234) in a particular orphanage

showed visible symptomology of “prenatal alcohol exposure” (p. 531). This prevalence rate was determined through a multi-level examination that included file reviews, growth measurements, and an assessment of children using the phenotype or facial screening assessment (Astley & Clarren, 1996). Developmental assessments were reviewed for 112 children, of whom “21 (19%) had mild delays, 45 (40%) had moderate delays and 12 (11%) had severe delays.... More than 70% of children with high phenotypic scores were categorized as moderate or severe delay” (Miller et al., 2006, p. 536). There are multiple conditions in institutions that contribute to the developmental problems of children living in congregate care where there are limited opportunities for stimulation.

▶ **Figure 1**  
Developmental assessments reviewed for 112 children







The diagnosis of adults is an evolving field and is in its early origins. At present, Sullivan (2008), specifically in reference to adults, has suggested that because “diagnosis still rests upon retrospective information, and often is not made until the life trajectory is firmly set, these patients may be referred for psychiatric evaluation from a wide range of settings” (p. 215). Concerns related to mental health are substantial, and Sullivan (2008) focused on the underlying vulnerabilities and problems in life adaptations, including “poor parental role modeling, disturbed development of trust and identity, patterns of avoidant coping behaviour, dysfunctional adolescents and adult relationships, and economic disadvantage” (p. 226). Major trend(s) in the new millennium in FASD research must include the evolution of research agendas that focus on post-diagnosis supportive practice and casework for adults. Diagnosis needs to be followed with a response that includes developing a support system and case planning tailored to the specific needs of the individual.

### 1.3

## Need for Adult Assessment and Diagnosis

There are several reasons why there is a need to address adult diagnosis and assessment. First, FASD has been identified as a major public health concern in Canada and other international jurisdictions (Moore et al., 2007; Peadon, Fremantle, Bower & Elliott, 2008; Warren et al., 2001). FASD is recognized as a disability that is expensive to manage, and these concerns are magnified because the condition is preventable through abstention from alcohol during pregnancy. This has prompted many Canadian provinces to make, or to engage in the process of making strategic plans for preventing FASD, as well as to identify and intervene with children, adolescents and adults diagnosed with one or more of the multiple conditions associated with FASD. In part, the substantial response to the needs of children for diagnosis and treatment of FASD has paved the path in terms of recognition that similar services are required for many adults who are undiagnosed and demonstrating struggles associated with FASD. As these strategic provincial plans are enacted and public awareness raised, it can be expected that more adult referrals will be made to the diagnostic clinics and programs that exist or that will be established as part of the resources to implement these plans.



Second, epidemiological estimates for FASD within the general population have been established, having been extrapolated from clinical and research data. However, there are no estimates of how many children are actually diagnosed with FAS or its related disorders in Canada, or how many children grow to adolescence or adulthood without an appropriate diagnosis (Clarren & Lutke, 2008). We do know, however, that adults are presenting themselves at diagnostic clinics or programs with suspected FASD but have operated below the diagnostic radar to date. Clarren and Lutke (2008), in a 2006 survey, identified a total of 27 programs in Western and Northern Canada engaged in FASD diagnostic activity. They reported an astounding rate (67%), of those referred to clinics, receiving some form of FASD diagnosis. This research identified the concerns about the lack of prevalence rates for Canada, while highlighting the need for ongoing diagnosis, research and diagnostic consistency.

This highlights a third need for adult assessment and diagnosis information – the inconsistency of diagnosis in relation to adults. There are many adults who are never diagnosed, misdiagnosed and even self-diagnosed as having an FASD. Standard practice in relation to diagnosis for adults is not well established in Canada or elsewhere. The potential exists for the successful strategies used in the diagnosis of children and adolescents to be applied to adults, as evidenced by the strategies of the few existing clinics that diagnose adults in Canada (Clarren & Lutke,

2008). It is also important to understand and codify the differences that should be taken into account when dealing with an adult population not previously diagnosed. With greater clarity around diagnosis, efforts could be initiated to have FASD recognized as a disabling condition that requires funding by governments, designated for assessment and support services. Perhaps this will lead to services related to diagnosis and assessment being covered by provincial health care.

There is a need to alert health, mental health, the justice system and social service workers to the similarity and differences in diagnostic criteria when dealing with adult populations as opposed to children. These professionals will be among those likely to be screening clients whom they suspect may have one of the disorders associated with exposure to alcohol in utero. Providing screening standards and tools could mean that vulnerable adults begin to receive the understanding and services appropriate to their needs.

Accurate diagnosis is important since many secondary conditions could be prevented with appropriate intervention (Malisza et al., 2005) or their effects reduced to improve the quality of life for individuals with FASD (Streissguth, 1997). These conditions (e.g. mental health concerns) make it difficult for affected individuals to function. They know that they struggle, but in the absence of a diagnosis, they do not understand or know “why.” Capital Health Edmonton and Area (2005) in its learning module for health and social



service workers outlines two primary reasons why it is important to conduct adult diagnosis of FASD. First, some secondary conditions associated with FASD (e.g. trouble with the law, mental health issues, transience and homelessness) can be overcome or their impact reduced with intervention and support (Streissguth, 1997). Affected persons can be referred to diagnostic, advocacy and support services that will assist them in their daily life, their relationships and employment. Second, both they and their support network often experience relief when they understand the root cause – a disabling brain injury – which accounts for many of the difficulties experienced. This rationale for adult diagnosis was reiterated by the Asante Centre (2008) in British Columbia, which recognizes that a benefit of receiving an adult FASD assessment and diagnosis is that individuals have an opportunity to understand themselves better through recognizing their unique set of strengths and weaknesses, and may receive answers as to why they have experienced the challenges they have faced throughout their life.

The Asante Centre also recognizes that adults with an FASD diagnosis may then have access to services that are better able to meet their needs, and could help others know how best to offer support. The Lakeland FASD Centre located in Cold Lake, Alberta, which covers a vast rural area, began adult diagnosis in 2000 (McFarlane & Rajani, 2007). Key issues for the 22 adults diagnosed through this clinic between 2001 and 2004 were employment, physical health,

mental health, justice issues, independent living, finances and addictions. The relevance of diagnosis to these adults is that supports can be delivered through individual planning in order to assist them in negotiating these challenges while living in their communities.

The establishment of diagnostic clinics for adults will assist them in their multiple roles as members of the communities where they live. Diagnosis through a comprehensive assessment process will help adults know more about their strengths and limitations. This information will also support them in mediating the challenges posed by the diagnosis as well as the development of support systems around daily living and community participation. There are good examples with FASSY (YK), Sheway (BC) and Breaking the Cycle (ON).

# 2.0 Literature review methodology

■ This section provides an overview of the approach and methodology used to identify the relevant literature from the peer-reviewed research literature and a select number of web-based and practice literature.

## 2.1

### Approach and Methodology

A structured approach was used to determine the source of materials for review. The peer-reviewed literature was the main source of information and data about diagnosis and assessment of adults with FASD. However, a certain amount of grey literature was located by consulting with a select group of FASD researchers and service providers, who identified sources outside the quality scholarly literature databases.

## 2.2

### Peer-Reviewed Literature: Search and Review Strategies

Searches for peer-reviewed journal articles and dissertations were conducted using the University of Calgary online databases in the area of Health Sciences and Medicine. These searches are outlined below. The Google Scholar search engine was also used to conduct more general searches. All searches were limited to research with humans, published in English.



The following searches were conducted:

Database Searched	Terminology in Abstract	Articles Selected
Ovid with all search engines, including CAB Abs, Global Health, ERIC, EMBASE, CDSR, ACP Journal Club, DARE, CCTR, CLCMR, CLHTA, CLEED, AMED, HealthSTAR, PsycINFO, Your Journals@Ovid, Ageline, Journals@Ovid, Ovid MEDLINE(R)	FASD or fetal alcohol spectrum or fetal alcohol syndrome AND adult	36
Ovid Healthstar <1966 to August 2008>	Fetal alcohol or FASD or fetal alcohol syndrome or fetal alcohol AND adult	57
Ovid MEDLINE(R) <1950 to September Week 3 2008>	FASD or fetal alcohol or foetal alcohol spectrum or fetal alcohol syndrome or FAS AND adult	37
Pub Med	FASD or fetal alcohol AND adult	19
All University of Calgary databases	FAS or foetal alcohol or fetal alcohol or FAS or FASD AND adult	8
Faculty of 1000 Medicine	FAS or foetal alcohol or fetal alcohol or FAS or FASD AND adult	0
ISI Web of Knowledge	fetal alcohol AND adult NOT rat	3



Key criteria were used in the decision tree for selecting articles for inclusion/exclusion in the literature review. We located each document and reviewed the abstract or entire document if there was no abstract to determine if the document met our inclusion criteria. The following describes the inclusion/exclusion criteria.

**Inclusion criteria.** We included documents that discussed diagnosed FASD, and the related categorical diagnoses in adult humans. We also included some studies of adolescents when it was thought to contain diagnostic and assessment information that might be relevant to adults.

**Exclusion criteria.** We excluded documents that were not in English, papers on animal studies and papers without an FASD or related diagnosis. No documents were excluded based on date of publication.

During the canvass of key informants for websites and practice-based literature that should be included in the review, several suggested peer-reviewed articles that had not been captured in the original searches. A third source of documents came when published articles were reviewed for important references that had been missed in the online searches but were presented in the reference lists of key journal articles. This is known as a “go backwards” approach (i.e. review citations for selected articles to determine prior articles to consider). When there was an important researcher identified, a “go forward” (i.e. use of citation indexes to identify articles citing important references) approach was used to identify any new relevant citations.

Once abstracts had been identified as relevant to the criteria and worthy of further exploration, the full article was accessed. The articles were skimmed, after which a further selection was made based on criteria including the terms discussed in the literature review outline and proposal. As well, articles were included if they were relevant to diagnosis. Articles were considered even if they did not explicitly refer to adults in the research, but if they referred to symptoms possibly developing in adulthood.

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## 2.3

### **Practice and Other Literature: Search and Review Strategies**

Literature database searches are often constrained by the coverage of the databases, the key words adopted, and the journals included. The research team, therefore, conducted additional searches for information from Internet websites for practice information. For example, some agencies have a described protocol for the diagnosis and assessment of adults. A description of their procedures and protocols was informative. The web searches involved locating agencies in Canada and the United States, which were identified through general Google searches or by key researchers known to the research team.



The following websites were reviewed:

Website	Website URL
DCFS Web Resource: Children and Substance Abuse	<a href="http://dcfswebresource.prairienet.org/ras/childsub.php">http://dcfswebresource.prairienet.org/ras/childsub.php</a>
National Organization on Fetal Alcohol Syndrome	<a href="http://nofas.org">http://nofas.org</a>
University of Washington: Fetal Alcohol and Drug Unit	<a href="http://depts.washington.edu/~fadu">http://depts.washington.edu/~fadu</a>
University of Washington: Fetal Alcohol Syndrome Diagnostic and Prevention Network	<a href="http://depts.washington.edu/fasdpn">http://depts.washington.edu/fasdpn</a>
FASlink: Fetal Alcohol Disorders Society – home page	<a href="http://www.acbr.com/fas/">http://www.acbr.com/fas/</a>
FASlink: Fetal Alcohol Disorders Society – archives	<a href="http://www.acbr.com/fas/faslink.htm">http://www.acbr.com/fas/faslink.htm</a>
U.S. Department of Health and Human Services and SAMSHA's National Clearing House for Drug and Alcohol Information	<a href="http://www.health.org/nacoa">http://www.health.org/nacoa</a>
Al-Anon/Alateen	<a href="http://www.alateen.org">http://www.alateen.org</a>
Alcohol Related Birth Injury (FAS/FAE) Resource Site	<a href="http://www.arbi.org/suppserv/supgroups.html">http://www.arbi.org/suppserv/supgroups.html</a>
Calgary Fetal Alcohol Network	<a href="http://www.calgaryfasd.com/">http://www.calgaryfasd.com/</a>
FASD Support and Resources in Alberta	<a href="http://fasd.typepad.com/fasd_support_in_alberta/2007/02/chrysalis_edmon.html">http://fasd.typepad.com/fasd_support_in_alberta/2007/02/chrysalis_edmon.html</a>
Renfrew Educational Services: Fetal Alcohol Spectrum Disorders Diagnosis and Intervention Services (FASD)	<a href="http://www.renfreweducation.org/desktopdefault.aspx?tabID=35">http://www.renfreweducation.org/desktopdefault.aspx?tabID=35</a>
Public Health Agency of Canada: Fetal Alcohol Spectrum Disorder	<a href="http://www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php">http://www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php</a>
Public Health Agency of Canada: Background of Government of Canada and FASD	<a href="http://www.phac-aspc.gc.ca/fasd-etcaf/goc-bg-eng.php">http://www.phac-aspc.gc.ca/fasd-etcaf/goc-bg-eng.php</a>
FAS Bookshelf Inc.: FAS Links	<a href="http://www.fasbookshelf.com/links.html">http://www.fasbookshelf.com/links.html</a>
Health Canada: Fetal Alcohol Spectrum Disorder	<a href="http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/fasd-etcaf-eng.php">http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/fasd-etcaf-eng.php</a>
FASCETS – Diane Malbin's work can be adapted for use in adult diagnosis according to another member of the NAT.	<a href="http://www.fascets.org/">http://www.fascets.org/</a>
Fetal Alcohol Syndrome/Fetal Alcohol Effects Outreach Project	<a href="http://www.faseout.ca/eng/home.htm">http://www.faseout.ca/eng/home.htm</a>
Canadian Centre on Substance Abuse	<a href="http://www.ccsa.ca/">http://www.ccsa.ca/</a>
FASD Community Circle in Victoria. There is a three-year project taking place in relation to adult diagnosis and it has several instruments developed. The contact is davidgerry@shaw.ca.	<a href="http://www.fasdconnections.ca">http://www.fasdconnections.ca</a>



Information on FAS/FASD is developed by practitioners or community groups, so it was important to review websites for relevant unpublished resources, including tools, checklists, organizational descriptions, program development, workshops and descriptive experiences from adults living with or caring for an adult living with FAS/FASD. Searches were performed on Google with the following terms:

FAS
FASD
FASD and Canada
FAS and Adult
FAE and Adult
Fetal Alcohol and Adult
Fetal Alcohol and Adult and Diagnosis
Fetal Alcohol and Diagnosis
FAE

## 2.4

### Processing the Literature

The resulting literature included over 100 peer-reviewed journal articles and practice-related documents. Each document was inventoried to categorize the information for further analysis. A concept-centric approach was used to review and classify the studies collected. This involved the creation of a concept matrix to review,

synthesize and critically analyze the literature and data located on adult diagnosis and assessment. Once the concept matrix was complete, documents could be grouped, summarized and critically analyzed.

The inventory consisted of classifying articles under the following headings and subheadings:

<b>Screening/Referral: Populations (adult, adolescent, child); Screening Process; Screening Tools/Techniques</b>
<b>Diagnosis: FAS; pFAS/FAE; ARBD; ARND; comorbid</b>
<b>Assessment Tools/Techniques: Cognitive; Physical; Emotional; Behavioural</b>
<b>Emerging Issues: Culturally Appropriate; At-risk Population; Absent Features; Multidisciplinarity</b>
<b>Type of Evidence: Conceptual; Evidence-based; Practice-based; Incidence/Prevalence</b>
<b>Notes: Important highlights, findings or other relevant</b>

In total, over 100 adult relevant documents were inventoried.<sup>3</sup> The investigators then reviewed and analyzed all of the inventoried documents. In addition, classic research and review articles were included in the bibliography because they provided necessary contextual material for the literature review of adult assessment and diagnosis.

<sup>3</sup> The inventory of the adult-related literature reviewed is included as a separate document



## 3.0 Literature review: adult diagnosis and assessment

- Increased attention in the literature is emerging in relation to adults and FASD. As the original cohort of infants and children diagnosed in the 1970s and 1980s has reached adulthood, many of them are now being re-examined to gain a better understanding of what FASD looks like in adults compared with children (e.g. Barr et al., 2006; Lemoine, 2003; Streissguth, Barr, Kogan & Bookstein, 1997). A goal of this literature review was to identify evidence- and practice-based literature that could assist health care and other professionals to recognize the disorders associated with FASD in adults, so timely assessment, diagnosis and service planning could happen. This goal is in keeping with the adult face of FASD presented in the literature over the past decade or so.

One of the clinical practice issues driving the diagnosis of adults is related to child welfare interventions. The Lakeland Centre for FASD, for example, found that 60% of its adult clients who had been diagnosed with some form of FASD had children, and many of those children (40%) were living in the care of others (McFarlane, 2008). The high incidence of children in care was also mentioned by Dubovsky (2008) when he referred to an unspecified study where

- ▶ **“over 80% of children and adolescents with an FASD were in foster or adoptive homes”**

(Slide #22), and by Hutson (2006), who cited a report from the Child Welfare League of Canada in 2003 that estimates that “50% of children in care in Alberta have FAS” (p. 2). So, when children are suspected to have or diagnosed with an FASD, the concern for the family rises because the reality is that parents themselves

may have an FASD. In such cases, the availability of a diagnostic clinic, which is accessible and prepared to do adult assessments, would be very helpful in order to assess/diagnose these adults in a consistent and coherent fashion. Such clinics could be instrumental in establishing support plans that recognize the unique needs of such individuals and families. When authorities, such as child protection practitioners, have become engaged in the lives of children and families where concerns of substance misuse is an issue and referral for adults is required, the assessment is now usually done on a fee-for-service basis.



The diagnostic process set out in the Canadian guidelines provides the overarching context for diagnosis of FAS and its related disorders in Canada (Chudley et al., 2005). These guidelines seek to harmonize those created by the U.S. Institute for Medicine (1996, as cited in Hoyme et al., 2005) and the 4-Digit Diagnostic Code (Astley & Clarren, 2004). The use of these diagnostic tools requires testing in multiple domains by specialized professionals. The first step in this process is potential case-identification and referral to a specialized assessment team.

### 3.1

#### **Screening and Referral Processes and Procedures**

Identification and referral are the first steps in the diagnostic process. Referral should be initiated at the point when a professional begins to suspect an alcohol-related disorder may be involved. This most often occurs when adults present with problems whose symptoms may be representative of FAS/FASD. The National Task Force on FAS/FAE et al. (2004) in its document, *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*, suggested that the referral process demands a “thorough knowledge of the physical and neurodevelopmental domains affected in individuals with FAS, as well as characteristics that could trigger a referral” (see Bertrand, Floyd & Weber, 2005, p. 7). The Centers for Disease

Control and Prevention’s (2005) guidelines contain a section on identifying and referring individuals with FAS, as do the Canadian guidelines (Chudley et al., 2005). These guidelines were developed with the idea that when in doubt, it was preferable to refer for full evaluation by a multidisciplinary team with experience in evaluating fetal alcohol exposure and its associated problems. However, in many instances, a multidisciplinary team is not available and the primary care physician may be called upon to complete the diagnosis. Referral to a multidisciplinary team (e.g. dysmorphologist, clinical geneticist, mental health professional and social worker) is preferable for two reasons. First, it is often necessary for diagnosis because the growth, central nervous system (CNS) deficits and facial features of FASD can overlap other syndromes and disorders, making a differential diagnosis difficult for those less trained to assess these characteristics. Also, even for those who clearly meet diagnostic criteria, referral to a specialized team allows for a complete assessment and the development of an individualized management plan. This plan is essential if appropriate services and treatment are to be provided.

For children and adolescents, the most likely people identifying potential FASD in an individual are medical, educational and social service professionals (Centers for Disease Control and Prevention, 2005). For adults, primary care physicians, mental health professionals, family members, those working in policing or justice fields, or those in their support network,



and the person themselves are the most likely to be involved in identifying those who should be referred for a full diagnosis. The Lakeland Centre for FASD (McFarlane, 2005, 2008; McFarlane & Rajani, 2007), located in Cold Lake, Alberta, adds several other referral sources to this list based on its clinical experience: children's services, human resources and employment, and programs for persons with developmental disabilities. Anecdotal evidence from one diagnostic clinic speaks to the effectiveness of screening; of the 41 adults referred to the program, all of them received an FASD diagnosis once assessed by the multidisciplinary team (personal communication, Audrey McFarlane, Executive Director, Lakeland Centre for FASD, October 26, 2008). In an FASD clinical capacity study, Clarren and Lutke (2008) investigated 15 clinical programs in Western and Northern Canada (i.e. these researchers contacted 27 programs but only 15 responded). They reported that assuming that all 1,140 patients were requesting assessment for FASD "then two thirds were found to have some form of the disorder and a third of those had the clinically obvious forms – FAS or pFAS" (p. e225). They noted, however, that some of the patients referred to the clinic may have been referred for reasons other than suspected FASD, which would make the diagnosis rate even higher.

The major role of primary care, mental health or social service providers in the screening of adults with potential FASD diagnosis is in "case finding" or identification of previously undiagnosed adults (Applebaum, 1995), subsequently followed by referral to other health care team members. The referring person plays an important role leading up to diagnosis, by helping them to gather and complete documents that will be needed in the formal assessment process. Such documents may include a history of in utero alcohol exposure, medical reports from childhood, results of previous psychosocial assessments, etc.

For many, the first step in the process to a diagnosis is to be identified as belonging to a high-risk group where a family history of substance misuse may raise concerns. The second step is usually some form of screening. For FASD, neonatal maternal alcohol consumption would place someone in such a high-risk group. The Centers for Disease Control and Prevention (2005), in guidelines prepared for the National Center on Birth Defects and Developmental Disabilities



in the United States, suggested the following constitute criteria for referring children for a full FASD assessment:

- 1. In utero alcohol exposure is known**
- 2. In utero alcohol exposure not known but social and family history indicates:**
  - a. Parent or caregiver reports that a child has or might have FAS**
  - b. Premature maternal death related to alcohol use**
  - c. Focus on children living with an alcoholic parent**
  - d. Current or previous abuse or neglect**
  - e. Current or previous involvement with child PSAs**
  - f. History of transient caregiving situations**
  - g. Been in foster or adoptive care (including kinship care)**
- 3. In utero alcohol exposure not known but physical characteristics are present in some combination:**
  - a. facial features**
  - b. growth deficits**
  - c. CNS abnormalities**

In adults, the physical criteria, which are the main focus of the Center for Disease Control and Prevention guide, may be absent or significantly changed from those of childhood. Practice wisdom coming from the experiences of the Lakeland Centre, according to McFarlane (2008), indicated two important implications when screening for and/or assessing for FASD in adults based on the 41 cases they have examined to date. The first implication is that “brain dysfunction is present when facial features or growth may not be” (slide #17). The second is that “if adults do have facial features they are still prominent and not faded as previously thought” (slide #17). This is the experience at one clinic engaged in adult diagnosis and is, therefore, not generalizable to all populations. This highlights the need for more research to investigate the differences in physical characteristics that may or may not be present in the adult with different FASD diagnoses.

Nine screening tools were mentioned in the literature that may be helpful in deciding to refer an adult for full assessment. Many of these screening instruments were developed for the early identification of children with FASD, but could be adapted to suit the particular needs of an adult population. Several documents provided a detailed description of the screening tools, while others made available only sketchy overviews of the instruments involved.



Burd, Cox, Fjelstad and McCulloch (2000) suggested that the most useful tool for screening in clinical settings was the 4-Digit Diagnostic Code (Astley & Clarren, 1996), although this has been used mostly in non-clinical settings for diagnosis rather than screening. From this well-used diagnostic tool, Burd et al. (1999) developed a rapid (less than 15 minutes), evidence-based screening instrument form that professionals or paraprofessionals could use to screen for FASD (see Appendix A). This instrument presented the professional with 30 characteristics scored under six primarily physical domains: head and face; neck and back; arms and hands; chest; skin; and development. Scoring is done in a yes/no format, with a weighted score assigned to each item. For example, a yes response to mild to moderate mental retardation yields an item score of 10, while hearing problems would produce a score of 1. Burd and the other researchers in this group screened 1,013 school-aged children and found the instrument to be *sensitive* (detected 100% of true positives), and *specific* (correctly excluded people not having FAS 94% of the time). This screening tool would need to be tested with the appropriate populations to see if its sensitivity and specificity properties were upheld with adults, especially since it relies primarily on physical characteristics for screening.

Goh and colleagues (2008) critically reviewed and evaluated the published literature and practice methods for screening suspected cases of FASD according to their sensitivity, specificity, and positive or negative predictive value.

They reviewed seven tools suitable for screening children and adolescents: ① meconium screening (fatty acid ethyl esters in neonatal meconium); ② youth-justice screening tool (Asante Centre probation officer screening and referral form); ③ modified Child Behaviour Checklist; ④ facial dysmorphology; ⑤ maternal history of substance abuse; ⑥ The Clinic for Alcohol and Drug Exposed Children intake procedure; and ⑦ the Medicine Wheel. Based on assessments of ease of use, accessibility, cost, expertise, cultural appropriateness, factors to facilitate implementation and barriers to implementation, five of the seven screening tools were assessed as facilitating diagnosis of FASD in different populations. The chosen screening tools were the meconium screening; the Asante Centre probation officer screening and referral form; the modified Child Behaviour Checklist; maternal history of substance abuse; and the Medicine Wheel. The meconium screening and the Child Behavior Checklist are not appropriate for use in adult screening, but the other three screening tools selected – although meant for screening with children and youth – may prove useful in screening adults.

Grafman and Litvan (1999) presented a series of screening questions that can be used in the evaluation of frontal lobe (cognitive) functioning (see Appendix B). These include functional areas of impairment such as attention-concentration, predictive planning, adaptive planning, short-term planning, reasoning, thematic understanding, social skills, inhibition and motivation with their



potential prefrontal cortical area of involvement, and the neurobehavioural probe to assess specific behavioural manifestations. These are important areas of functioning that may indicate FASD impairment in adults.

Several attempts have been made to develop screening tools aimed at rapidly screening adolescents and adults within the justice system who do not have an FASD diagnosis. Fast, Conry and Loock (1999) identified that within the population of the youth justice system they sampled, 1% were diagnosed with FAS and 23% were diagnosed with alcohol-related diagnosis. This made screening in the youth justice system a necessity, and prompted the need for an FAS screening tool in order to identify those at risk of FAS or a related FASD diagnosis. Although Fast, Conry and Loock developed a screening form, enough detail about its content was not provided for a full description for this review. Another such example of a screening tool used in the justice system was provided by Boland, Chudley and Grant in 2002. They briefly described developing a screening instrument that was to be used in a study with adult offenders based on an empirically derived checklist of known characteristics of those with FAS, together with historical data, to determine who would be at high risk of having an FASD. However, no follow-up information was located to indicate the effectiveness of this instrument or any details about the items on the checklist.

A third screening instrument, the Fetal Alcohol Behavior Scale (Streissguth, Bookstein, Barr, Press & Sampson, 1998) has been used successfully to identify youth and adults at high risk for FASD-related disorders in several correctional facilities. It is a 36-item scale using a yes/no answer format that is completed by someone who knows the behaviours of the person being assessed well. The scoring is based on a simple calculation of the yes responses to items related to personal conduct, emotions, communication and speech, social skills and interactions, motor skills and activities, academic or work performance, and physical or physiological functioning. A series of studies was used to test the utility of the behaviour scale: ① a Derivation Study, which focused on reducing a lengthy checklist into the 36 items of the new scale; ② a Detection Study, which was used with 134 patients under the age of 35 years in a prison facility to detect those with FAS or FAE (fetal alcohol effects); ③ the Normative Study, which determined the sensitivity of the scale within a non-clinical sample of 186 adults waiting at a medical clinic who had children of any age, and established a high (0.89 Cronbach's coefficient) item-to-scale reliability; ④ the Test-Retest Reliability Study in which 41 patients from previous studies who had completed forms from two different time periods were evaluated by the same person; and ⑤ the Prediction Study, which used information about 70 adults with FAS/FAE diagnosis and had information from a life history interview with a caretaker, spouse or informant. One of the benefits of the Fetal Alcohol Behavior Scale (FABS) is that it appears not to be age,



sex and/or race specific. All the information to date on the FABS has been gathered in research settings and information as to its performance in clinical and screening contexts would solidify its usefulness.

The OBD Triage Institute, which began in 1998 in Alberta, has developed a pre-screening tool that has been used in Alberta and many other provinces in Canada in relation to both children and adults (Lawyrk, 2008). The Triage Assessment model takes into consideration the concern that biological parents of children referred for assessment may also be alcohol affected. Both children and adults have been referred to the Institute, which has worked extensively with child welfare, youth justice and the adult corrections system. The instrument is reported to be sensitive to both children and adults, and post-screening appropriate referrals are made to diagnostic clinics for FASD. It appears that this screening tool is strongly based on a reiteration of the 4-Digit Diagnostic Code. Individuals screened out are referred to other appropriate resources. The four primary criteria, which are grounded in the work of previous research (Streissguth, 1997), screens for:

- 1. confirmation of maternal ingestion of alcohol (drugs) during pregnancy and/or evaluation of statistical inference indicators based on established research findings**
- 2. physical anomalies, including sentinel craniofacial features, growth delay, dysmorphic physical findings and medical issues found more commonly in alcohol- and/or drug-affected individuals**
- 3. neurodevelopmental deficits and/or skewed learning patterns**
- 4. persistent behavioural issues medically documented to occur more frequently in alcohol-affected children, youth and adults**

How might a screening tool intended for use with children or adolescents be adapted for those who are already adults? Streissguth et al. in 1991 examined FAS in adolescents and adults and found some important differences when compared with diagnosis in children. Some of the physical characteristics described by Streissguth and colleagues could be used to adapt previous screening tools for an adult population. Also, the inclusion of more cognitive, neuropsychological and learning disabilities related to findings about FASD effects in late childhood (Streissguth, Barr, Kogan & Bookstein, 1997) could strengthen the screening for FAS and its related disorders in adults.



Screening for referral to a diagnostic clinic is an important function that would benefit from a consistent approach. Fast and Conry (2004) were clear that

► **“screening tools for FASD need to be developed and validated”**

(p. 162). The purpose of such screening tools would be to identify individuals at high risk of having FAS or one of its related disorders. However, such tools should not be mistaken for or be misused to diagnose FASD. Diagnosis can be made once referral to a professional with specialized training or to a team of professionals that can administer the necessary medical and psychological assessments has taken place. There are lists of FASD diagnostic clinics and resources available for many areas (e.g. the Alberta FASD Diagnostic Clinics list put out by the Psychologists’ Association of Alberta, and the online document *Creating a Foundation for FASD Diagnostic Capacity* by Guilfoyle (2006) that provides a number of assessment resources in Ontario). Also, there are websites that provide information about adult diagnosis resources such as the CanNorthwest FASD Project’s project inventory, which has a description of resources and research taking place in British Columbia and Yukon.

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## 3.2

### The Diagnostic Clinic/Program

The U.S. Institute of Medicine (1996, as cited in Hoyme et al., 2005) suggested that while trained clinicians (e.g. psychologists) may diagnose the neurobehavioural aspects of FAS, dysmorphologists who are trained to assess the medical abnormalities are essential for a complete medical diagnosis. This division is reflected in much of the FASD literature where medical researchers explore the structural abnormalities and psychologists focus their research on the neurological damage incurred through in utero alcohol exposure, and the subsequent cognitive and behavioural impairments that endure (Pei & Rinaldi, 2004). The practicality related to the need to have both medical and psychological expertise in the diagnosis of FASD often presents challenges, as regular medical clinics are usually not set up for this diversity in expertise. Thus, across Canada and internationally, specialized clinics or programs have been set up to facilitate the diagnoses of fetal alcohol-exposed children, adolescents and adults resulting in FASD.





▶ **“Because there is no definitive test for FASD, researchers and clinicians diagnose FASD symptomatically and then look back to these abnormalities to better refine diagnosis”**

(Pei & Rinaldi, 2004, p. 126). A multidisciplinary team for assessment is usually called upon to participate in the diagnostic process, as the symptomology for FASD is varied and some aspects change across the lifespan of the person affected (Chudley, Kilgour, Cranston & Edwards, 2007). These specialized teams may be housed in a hospital or community health clinic. Virtual and mobile teams can be created in regions where distance is an obstacle to diagnosing children, adolescents and adults with FASD (Chudley, Kilgour, Cranston & Edwards, 2007; Guilfoyle, 2006; McFarlane & Rajani, 2007). Team members usually include at minimum a physician with expertise in birth defects and different anomalies such as facial dysmorphism and other physical health issues related to FASD. A psychologist is included as part of the team, as well as a nurse clinician, social worker, occupational therapist, educators and a speech language pathologist, and may involve additional members such as family advocates if required (Boland, Chudley & Grant, 2002; Chudley et al., 2005). Diagnostic

teams vary in their membership, dependent on resources available in different communities. Some resources are available to guide the establishment and team development required for such a diverse and highly trained team (Dewane, Scott & Brems, 2005). Appendix C provides a description of team member roles from the Vancouver Island Health Authority’s pilot project diagnostic clinic, which may be typical of such multidisciplinary teams.

A recently published research article by Peadon, Fremantle, Bower and Elliott (2008) surveyed 34 FASD diagnostic clinics in North America, South America, Africa and Europe that conducted FASD assessments for children. While 85% of completed questionnaires came from North American clinics, the remaining 15% from South America, South Africa, Italy and the United Kingdom remind us that FASD is truly an international phenomenon. Although the focus of this study was on child diagnosis, their explorations into the diagnostic process, the models for service used, and the comparison of clinical practice as recommended by published guidelines parallel the investigations found in this section of the literature review on adult diagnostic services in Canada.

Peadon, Fremantle, Bower and Elliott (2008) reported the following results. As recommended in diagnostic guidelines, assessments were completed by a **multidisciplinary team** in



97% of the clinics surveyed. In 94% of clinics, some members have *specific training* in the area of children exposed to alcohol in utero. *Neurobehavioural assessments* were part of the diagnostic process in 94% of the cases reported. Only 24% of the clinics had no *referral criteria* specified. Approximately 15% of the clinics surveyed reported that they provided diagnostic services to individuals of *any age*; an additional 15% were exclusively for children; and the remainder served infants, children, adolescents and a few young adults. *Funding sources* were queried, and it was reported that 26% of the clinics charged some form of fee-for-service. One such clinic was located in Canada and the remaining eight were in the United States. The clinics in South America, South Africa, Italy and the United Kingdom received funding from research grants and/or federal funding. These were also sources of funding used in the Canadian and American clinics. A full study of Canadian clinics and teams providing assessments to adults would add greatly to our understanding of what is already taking place in this area and could form the beginnings of a best practice model that focuses on a consistent approach to assessment and diagnosis.

### 3.3

#### Assessment Process and Procedures

The next step in the diagnostic process is the intake procedures at the FASD clinic or program (see Appendix D for a pre-assessment checklist). Dewane, Scott & Brems (2005) explained that this may include an assessment of eligibility for diagnostic services by one member of the team (usually the team coordinator) based on the documents filed and the criteria determined by the team. Some potential eligibility criteria may include age requirements, confirmation of fetal alcohol exposure, severity of client symptomology, reason for referral, level of need, current level of support received through community services, or usefulness of diagnosis.

Several resources described a clinic-based model where the individual is scheduled for a one-day clinic, during which all assessments are conducted by respective practitioners and a diagnosis is derived by the end of the clinic day (Dewane, Scott & Brems, 2005; McFarlane, 2008). Some psychological testing may require up to a half-day longer so the assessment is spread over a two-day period. The clinic concludes all assessments, interviews, collation of information, diagnostic determination, recommendations and report writing on clinic day (McFarlane, 2008). The diagnosis and recommendations are usually presented during



a meeting with the client and members of his or her support network. At this meeting, the team usually introduces the diagnostic code and explains the results. Team members have an opportunity to share their observations and recommendations. Questions from the individual and family or friends who are supporting the person can be addressed at this time, as well as the scheduling of any follow-up sessions and/or referrals to other community resources.

The following are examples of Canadian diagnostic clinics assessing adults for FASD.

#### A. Adult Assessment and Diagnostic Project

The Adult Assessment and Diagnostic Project is located in Whitehorse, Yukon. It is a pilot project that began in March 2005 and will continue until the end of the pilot project period in March 2009. The project provides assessment/diagnosis to adults in Yukon with priority given to those at risk of prison and those attempting to parent. Also included in the service is the development and implementation of a plan of action based on the results of the assessments and recommendations of the team. To date, 28 adults have been assessed and 26 have been diagnosed with an FASD. One is undergoing additional medical tests.

#### B. The Asante Centre for Fetal Alcohol Syndrome

The Asante Centre for Fetal Alcohol Syndrome in British Columbia outlines the following adult assessment process in its material:

1. **A referral to the clinic is made either as a self-referral (for which the Centre has a family nurse clinician and family support worker who will assist the person in gathering the information needed for the assessment) or physician referral. The documentation that is needed includes birth records, medical records, school records, past assessments, and confirmation of alcohol use by mother.**
2. **As stated in the material from the Asante Centre, the actual assessment, which takes one and a half to two days, has four components:**
  - a. ***medical assessment* where a medical doctor measures eyes and other facial features, assesses fine and gross motor skills, reflexes, height, weight and hearing**
  - b. ***psychological assessment* involves tests of memory, problem-solving skills, academic abilities and cognitive abilities**
  - c. ***speech and language assessment* to examine communication skills and patterns**
  - d. ***interviews* with the person being assessed plus other people who act in supporting roles to learn about their needs.**



### C. The Lakeland FASD Centre

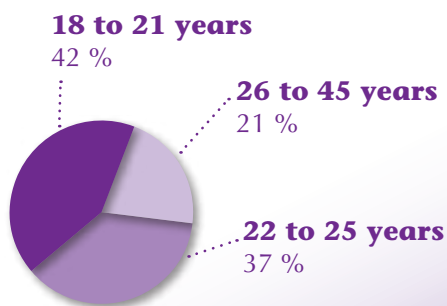
The Lakeland FASD Centre located in Cold Lake, Alberta, which covers a vast rural area, began adult diagnosis in 2000. Its diagnostic team consists of a physician, neuropsychologist, mental health therapist, legal representative, persons with developmental disabilities (PDD) coordinator, Aboriginal liaison worker, addictions counsellor and team coordinator. Its assessment model includes a pre-clinic phase where the team coordinator completes the initial intake form and uses this information to determine eligibility for a full assessment. The basic criteria needed to proceed are confirmed history of fetal alcohol exposure and residency in the catchment area covered by the clinic.

The fee is currently \$1,000 to offset the costs of the neuropsychologist and physician. Additional costs include physician compensation for costs associated with being away from the office and billing for one patient through the diagnostic clinic. The clinic concludes all assessments, interviews, collation of information, diagnostic determination, recommendations and report writing on clinic day. Concerns exist about adults not showing up for scheduled clinic day when the team is assembled and ready to work.

- ▶ The clinic has seen 41 adults to date ranging in age from 18 to 45 years: 18–21 (42%), 22–25 (37%) and 26–45 (21%). There is an almost even split between females (55%) and males (45%) seen at the clinic. All of these adults received a diagnosis of one of the conditions along the spectrum of FASD. Most adults assessed at the clinic received an ARND diagnosis, had significant health issues (95%) and had an IQ over 70 (71%). Most of the adults seen at the clinic have children (60%) but 40% of these parents have children in the care of others.

**Figure 2**

41 adults from 18 to 45 years seen by the clinic



Key issues for 22 adults diagnosed in this clinic between 2001 and 2004 were employment, physical health, mental health, justice issues, independent living, finances and addictions. The relevance of diagnosis is that adults who are diagnosed can be provided supports through individual planning in order to assist in negotiating these challenges in their communities.



McFarlane and Rajani (2007) provided an analysis of critical factors and challenges to the success of FASD diagnostic clinics in rural areas specifically but to all diagnostic clinics generally. Critical factors included team selection and coordination as well as the development and management of the team. A commitment to client/family-focused services and establishing cultural connections within the community were also identified as important features of a diagnostic clinic model.

### 3.4

#### **Diagnostic Criteria and Decision Making**

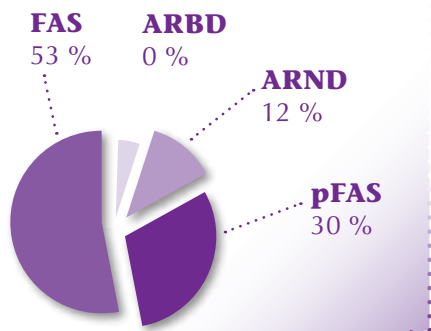
The clinical assessments are the most critical elements of the diagnostic process. The process is complex and “requires consideration of multiple professional domains” (Fryer, 2008, p. 18). The following section will present primarily evidence-based literature describing the research support for diagnostic considerations when assessing adults and tools/techniques that have been used in the diagnostic process. Detailed diagnostic protocols for FAS and related disorders are available for children and adolescents but are only in the infancy stage for adults (Astley & Clarren, 1999, 2000; Burd & Martsolf, 1989).

FASD is a series of multifaceted conditions – a wide range of characteristics, which are variable and age dependent, but which need to be considered when diagnosing FAS and its related disorders (Burd, Cotsonas-Hassler, Martsolf & Kerbeshian, 2003; Streissguth et al., 1991). Pei and Rinaldi (2004) reported that the Institute of Medicine’s report in 1996 addressed the previous lack of diagnostic clarity by identifying a range of birth defects and disabilities caused by fetal alcohol exposure. Each of these FASD categories was based on the traditional four diagnostic criteria (i.e. fetal alcohol exposure; growth deficits; neurodevelopmental and behavioural characteristics; and distinctive facial features) but with increased detail and specificity. Diagnoses under the FASD umbrella include: **1** Fetal Alcohol Syndrome (FAS), which refers to a person who has slowed growth, certain facial features and brain abnormalities; **2** Partial FAS (pFAS), which refers to individuals who have some but not all of the FAS characteristics – this was previously referred to as fetal alcohol effects (FAE); and **3** Alcohol-related Neuro-developmental Disorder (ARND), which encompasses a range of CNS dysfunctions associated with in utero exposure to alcohol. The other major category included under the FASD spectrum was Alcohol-related Birth Defects (ARBD), which was seldom mentioned in the evidence-based literature reviewed on FASD diagnosis. A breakdown by the four diagnostic types presented above was reported by a Finnish study (Autti-Ramo et al., 2006) of 77 individuals



aged 8 to 20 years who were assessed based on physical characteristics; 95% were diagnosed with FASD with the following breakdown across the spectrum of diagnoses:

**Figure 3**



These four diagnostic categories were adopted by the Canadian guidelines for FASD (Chudley et al., 2005).

Peadon and colleagues (2008) suggested that

► **“the diagnosis of FASD is complicated by the debate about the most appropriate diagnostic criteria”**

and the publication of multiple guidelines available in the past 10 years or so (p. 18). As a result, researchers and clinicians frequently use more than one set of diagnostic criteria or make their own adaptations to published guidelines according to Peadon’s survey results (i.e. almost

one-third of the clinics surveyed reported this finding). A consistent approach to diagnosis, including best practice evidence for assessment tools and techniques with adults, would greatly advance this field, and make for more readily accessible comparisons among research and practice findings.

Leading practice on diagnosis of FASD has emerged in North America from the standards set by the U.S. Institute of Medicine (Stratton, Howe & Battaglia, 1996) and the 4-Digit Diagnostic Code (Astley & Clarren, 1996). Diagnosis relies heavily on classification systems, which provide a portrait of the characteristics that constitute a particular condition or disease. Astley and Clarren, using the Washington State FAS Diagnostic and Prevention Network statistics, developed a new, comprehensive, reproducible method for diagnosing the full spectrum of outcomes of patients with fetal alcohol exposure. This new diagnostic method, called the 4-Digit Diagnostic Code, provided more accurate and reproducible diagnoses using quantitative, objective measurement scales and specific case definitions. The four digits in the code reflect the magnitude of expression of the four key diagnostic features of FAS: ① growth deficiency, ② the FAS facial features, ③ central nervous system (CNS) damage/dysfunction, and ④ fetal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale (i.e. 1 refers to the complete absence of the FAS feature and 4 to a strong “classic” presence). An individual’s 4-Digit Diagnostic



Code is derived after a thorough evaluation by an interdisciplinary team of professionals. This diagnostic tool has been used in numerous research and clinical cases, and has been adopted as the preferred assessment tool in the Canadian guidelines for diagnosis of FASD. Astley (2003) indicated that “over 50 multidisciplinary clinical teams across the United States and Canada are now using the 4-Digit Diagnostic Code in a wide array of clinical/social service settings” (p. 3). Chudley, Kilgour, Cranston and Edwards (2007) noted that “modifications of the 4-Digit Code are being used in many clinics throughout North America for use in the diagnosis of children and adults” (p. 264).

However, when assessing adults with potential FASD, adjustments are needed to be made under our current understanding and assessments (Chudley, Kilgour, Cranston & Edwards, 2007). Burd, Cotsonas-Hassler, Martsolf and Kerbeshian (2003) developed an instrument for assessing the severity of FAS and its related disorders (pFAS and ARND) in children, adolescents and adults (age range 1 month to 56 years). This preliminary instrument (see Appendix E) measures areas such as growth, facial features, comorbid neuropsychiatric conditions, sleep, services used and Vineland scores (i.e. Vineland Adaptive Behavior Scales), and is based on empirical evidence that comorbid mental disorders are strongly associated with diagnoses of FAS or pFAS. These authors urge the research and practice communities to lessen their reliance on dysmorphia (facial features and growth

impairment such as short palpebral fissure or absent philtrum) as the essential diagnostic feature of the spectrum of FAS and pFAS in favour of “the primary problem from prenatal alcohol exposure is brain damage or dysfunction manifesting as common disorders of development and as mental illness” (p. 704).

### A. Evaluating Dysmorphology

There are few published reports on dysmorphology in FAS adults. One such assessment was done by Streissguth et al. (1991) where 91 adolescents and adults with a FAS diagnosis were found to have less distinctive facial features than they did as children. However, three features often remained – eye anomalies, short palpebral fissures, and abnormalities of the philtrum and lips. These features remain useful in distinguishing adults with FAS who were not diagnosed as children. Other observations of physical changes were noted by Lemoine (2003) in his 25-year follow-up examination of 105 adults who had been assessed and diagnosed as children. He found that other facial anomalies had changed (e.g. nose and chin) while intellectual deficits and maladaptive behaviours persisted.

The traditional physical examination for dysmorphology would include growth measurements for height, weight and head circumference (Streissguth et al., 1991). FAS shifts the normal distribution of height and head circumference about two standard deviations down from the population mean for adolescents and adults.



However, Streissguth et al. (1991) found that 28% of their sample of adolescents and adults had normal head sizes, and 16% were within the average height range. FAS has been shown to have less consistent effects on weight, even though being underweight is very typical in young children with this disorder. Among the adolescents and adults in this 1991 study, 25% of those with FAS diagnosis and 50% of those with FAE (now known as pFAS) were not underweight. There were no gender differences on growth parameters noted, and no significant delay in the onset of puberty.

The other classical examination for characteristic facial features (i.e. short palpebral fissures, mid-face hypoplasia, smooth and/or long philtrum and thin upper lip) provides specificity for FAS but not other diagnoses within the spectrum (Streissguth et al., 1991). These facial features have been found to be among the most variable of the characteristics across FAS development (Burd, Cotsonas-Hassler, Martsolf & Kerbeshian, 2003). Streissguth et al. (1991) noted that facial characteristics became less distinctive over time, although these authors suggested that in many adolescent and adult cases “eye anomalies, short palperbaral fissures, and abnormalities of the philtrum and lips remain useful diagnostic feature” (p. 1964). However, there was continued growth in four facial areas mentioned in this study: ❶ nose in two dimensions – height of the nasal bridge and nasal length from root to tip; ❷ growth of the midfacial region correcting the

earlier midfacial hypoplasia; ❸ improved soft-tissue modelling of the philtrum and upper lip; and ❹ continued growth of the chin.

One of the challenges for clinicians, who are used to child diagnosis of FAS, is that most of those affected with FASD (i.e. with pFAS, ARND or ARBD diagnoses) may have no growth impairment and few, if any, dysmorphic features classic to FAS children (Chudley, Kilgour, Cranston & Edwards, 2007). Because of this, many adults who need a diagnosis have been missed or are perhaps misdiagnosed. Therefore, they enter adulthood without a proper diagnosis. Burd, Cotsonas-Hassler, Martsolf and Kerbeshian (2003) suggested that, given this situation, emphasis in evaluating adults should be placed on neurodevelopmental aspects rather than dysmorphia (i.e. facial features and growth impairment).

## B. Evaluating Brain and Neurological Abnormalities

The neuroanatomical effects of in utero alcohol exposure are well documented in the research literature. A series of research studies has investigated the CNS anomalies associated with FAS and its related disorders to better understand the brain functioning. Anatomical abnormalities in areas such as the corpus collosum, cortices and basal ganglia have been linked to developmental and behavioural deficits such as intelligence, language development, visual-spatial functioning and attention/memory problems (Bookstein,





Streissguth, Connor & Sampson, 2006; Mattson & Riley, 1997). Developments in magnetic resonance imaging (MRI) and functional magnetic resonance imaging (fMRI) technologies have made the mapping of these abnormalities in children, adolescents and adults more accurate and readily accessible (Swayze et al., 1997). For example, Malisza et al. (2005) evaluated the spatial working memory function of both children and adults with FASD using the fMRI technology. These researchers found that adults with FASD showed increased functional activity in the inferior and middle frontal cortex compared with the activity in age- and sex-matched controls. Sowell et al. (2002) found that brain growth continues to be adversely affected well into adulthood. The regions most affected by fetal alcohol exposure were frontal and inferior parietal, and may account for some of the behavioural deficits characterized by those affected by FASD. The maintenance of structural brain changes into adulthood led Bookheimer and Sowell (2005) to investigate the effectiveness of a functional (i.e. in assessing brain activation during working memory tasks) and structural MRI in adults with FASD. A challenge faced with fMRI results is that not enough data are available with control subjects to make a clear assessment of what level or magnitude of activation of specific brain functions is indicative of FASD impairment.

Bookstein, Streissguth, Sampson, Connor and Barr, in a 2002 published study, identified 35 distinguishing landmarks in the brains of 90 adults diagnosed with FAS when compared with those of non-FAS diagnosed controls using MRI imaging techniques. This same group of researchers published another study where they examined neuroanatomical features (size and shape of cerebellum; subcortical landmark point configurations, with the size and shape of the corpus callosum) associated with executive function deficits in a sample of 180 adolescents and adults (120 with existing FASD diagnosis and matched 60 controls) where damage was detected using MRI brain imaging (Bookstein, Streissguth, Connor & Sampson, 2006).

Using a related technology, the Fagerlund et al. (2006) study examined the brains of 10 adolescents and young adults diagnosed with FASD using magnetic resonance spectroscopy (MRS), and suggested that exposure to alcohol in utero appears to permanently alter brain metabolism (neurochemical alterations) in multiple areas of the brain (e.g. parietal and frontal cortices, corpus callosum). These findings provide support for the executive functioning deficits found by Kodituwakku, Kalberg and May (2001) and Mattson, Schoenfeld and Riley (2001), who found that individuals with FASD experienced difficulties with problem solving, and planning and flexibility in terms of thought processes.



Riley, McGee and Sowell (2004) summarized a decade of using brain imaging techniques to assess brain functioning with children and adults diagnosed with FASD. They concluded that microcephaly and structural abnormalities affecting the cerebellum, corpus colosum and basal ganglia were common in alcohol-exposed individuals. Most recently, Sowell et al. (2008) have used MRIs to investigate the patterns of brain dysmorphology in children and young adults. In this research, they are finding new associations between cortical thickness in certain areas of the brain in individuals with FASD when compared with controls. In the future, diagnostic testing may use brain imaging techniques to further our understanding of the mechanisms involved in the behavioural deficits long acknowledged in people with FASD.

The exploration of neuroanatomical abnormalities has produced consensus in the research community about the enduring effects of in utero alcohol exposure. The consequences of these deficits are reviewed in the next section as adaptive functioning is examined.

### C. Evaluating Neurodevelopmental and Neurobehavioural Deficits

#### ▶ **“The behavioral and cognitive effects of prenatal alcohol are among the most devastating consequences of such exposure”**

(Mattson & Riley, 1997, p. 4). Even so, “many symptoms are non-specific and no neurodevelopmental profile has been developed” reported Malisza et al. (2005, p. 1150). These

researchers found that adults with FASD showed increased functional activity in the inferior and middle frontal cortex compared with the activity in age- and sex-matched controls.

The range of neurological impairments explored in the research literature includes:

#### **microcephaly or history of developmental delay**

(Streissguth et al., 1991)

**attention deficits** (Kerns, Don, Mateer & Streissguth, 1997; Streissguth et al., 1991)

**cognitive, learning and/or intellectual deficits** (Kerns, Don, Mateer & Streissguth, 1997; Streissguth et al., 1991)

**seizures** (Streissguth et al., 1991)

**auditory and visual attention** (Chan, 1999; Connor, Streissguth, Sampson, Bookstein & Barr, 1999)

**verbal memory function** (Kerns, Don, Mateer & Streissguth, 1997)

**motor control** (Connor, Sampson, Streissguth, Bookstein & Barr, 2006)

Individuals with FASD often have many neurobehavioural problems, which interrelate to cause profound problems with accurately processing information and their relationship with the world around them. Impacting adult functioning are problems with impulse control and discerning cause-effect relationships; problems with the ability to generalize information; problems with



understanding concepts and abstract thinking; problems with short-term memory; and problems with processing information, particularly auditory information.

Investigations into the cognitive deficits manifested in adults who have sustained some degree of CNS dysfunction due to in utero exposure to alcohol have focused primarily on IQ and achievement testing in children, where their intellectual abilities generally fall in the below-average intelligence range. A few studies have followed this population into adulthood (Streissguth et al., 1991), and several studies have examined the cognitive deficits of adults with FAS who have IQ scores in the low-average to above-average range (Kerns, Don, Mateer & Streissguth, 1997). The Wechsler Adult Intelligence Scale – Revised or Wechsler Intelligence Scale for Children – Revised was the most common assessment tool used in research studies (e.g. Grant, Huggins, Connor & Streissguth, 2005; Kerns, Don, Mateer & Streissguth, 1997; Streissguth et al., 1991). Research in this area suggests that the implications of these findings may account for the functional difficulties that individuals living with FASD report in school, home and community settings.

Very little consistency in assessment tools and techniques was found in the clinical research literature for assessing academic and adaptive functioning. For example, the Addiction Severity Index (5th ed.), which assesses problem severity in seven domains, including medical,

employment, legal, family/social, alcohol and other substance abuse, and psychiatric/emotional was used by Grant, Huggins, Connor and Streissguth (2005), but not in any other research examined. In the same study, Grant and colleagues found that of the 11 women administered the Brief Symptom Inventory (53-item psychiatric symptom checklist), 55% were found to have symptom levels indicative of a psychiatric diagnosis. This finding was consistent with that of Famy, Streissguth and Unis (1998) but they used a different instrument to measure depression. In the follow-up study by Streissguth et al. (1991), the Vineland Adaptive Behavior Scale was used to assess adaptive functioning in people previously diagnosed with FAS. Assessment using this measure of adaptive functioning in the areas of daily living, socialization and communication skills indicated an average level of adaptive functioning at around seven years for the adolescents and adults involved in the study. This testing revealed problematic deficits in “failure to consider consequences of actions, lack of appropriate initiative, unresponsiveness to subtle social cues, and lack of reciprocal friendships” (p. 1965). All participants in this study were assessed to have either a “significant” level of this maladaptive behaviour (62%) or an “intermediate” level of dysfunction (38%). Poor concentration and attention dependency, stubbornness or sullenness, social withdrawal, teasing or bullying, crying or laughing too easily, impulsivity, and periods of high anxiety were



among the maladaptive behaviours noted. It is these types of adaptive deficits that are the focus of the next section.

#### D. Evaluating Secondary Sequelae

The primary deficits associated with FASD are characteristics and behaviours reflected in the brain structures and function of alcohol-exposed individuals (structural anomalies and behavioural and neurocognitive disabilities). Secondary consequences related to these primary conditions are considered those where the individual is not born with but rather develops them over time due to the poor fit between the person and his or her environment (Streissguth, Barr, Kogan & Bookstein, 1997); generally, they fall into the domain of social challenges. These are reflected in the three profiles of typical adults attending the Lakeland Centre for FASD (McFarlane, 2008).

**Adult Profile 1:** Has physical challenges; basic living skills are lacking; needs dependent living situation; has social skills problems; budgeting and employment are issues.

**Adult Profile 2:** Lack actual ability, although they present with an appearance of capability; demonstrate poor judgment; lack internal structure and the inability to advocate for self.

**Adult Profile 3:** Has mental health issues; substance abuse problems; may have sexual issues; demonstrated parenting challenges; may have legal issues or interaction with justice system.

In their review of some of the challenges of diagnosing FASD in adults, Chudley, Kilgour, Cranston and Edwards (2007) reported that the term “secondary disabilities” was introduced in 1996 by Streissguth and colleagues in a longitudinal study of children, adolescents and adults with FAS and FAE (now known as pFAS). Common secondary conditions reported in the literature include:

**mental health problems** (e.g. Barr et al., 2006; Bhatara, Loudenberg & Ellis, 2006; Boland, Chudley & Grant, 2002; Streissguth, Barr, Kogan & Bookstein, 1997; Wright and Associates, 2004)

**disrupted school experience** (e.g. Chudley, Kilgour, Cranston & Edwards, 2007; Clarke, Tough, Hicks & Clarren, 2005; Duquette, Stodel, Fullarton & Hagglund, 2006; Famy, Streissguth & Unis, 1998; Lemoine, 2003; Streissguth, Barr, Kogan & Bookstein, 1997)

**trouble with the law including confinement** (Chudley, Kilgour, Cranston & Edwards, 2007; Clarke, Tough, Hicks & Clarren, 2005; Famy, Streissguth & Unis, 1998; Lemoine, 2003)

**inappropriate sexual behaviour** (Chudley, Kilgour, Cranston & Edwards, 2007; Clarke, Tough, Hicks & Clarren, 2005; Famy, Streissguth & Unis, 1998; Lemoine, 2003)

**substance abuse** (Chudley, Kilgour, Cranston & Edwards, 2007; Clarke, Tough, Hicks & Clarren, 2005; Famy, Streissguth & Unis, 1998; Lemoine, 2003)



Exclusive to adults were three additional secondary conditions: **dependent living, problems with employment** and **problems parenting their children**. While the above present more as social problems, the following are more reflective of a secondary disability, particularly those diagnoses related to mental health. The Famy, Streissguth and Unis (1998) study of 25 adults with diagnosed FAS or FAE found that 92% met criteria for past or present alcohol or drug dependency; 48% for personality disorders, especially avoidant, dependent or antisocial personality disorders; 44% for depression; 40% for psychotic disorders; and 20% with bipolar and anxiety disorders.

Mental health problems associated with FASD have received a great deal of attention in the literature (e.g. Barr et al., 2006; Bhatara, Loudenberg & Ellis, 2006; Boland, Chudley & Grant, 2002; Streissguth, Barr, Kogan & Bookstein, 1997; Wright and Associates, 2004). Barr et al. (2006), in a 25-year longitudinal study of over 400 alcohol-exposed individuals (compared with those whose mother smoked cigarettes while pregnant), found that alcohol-exposed individuals were more than twice as likely to receive a diagnosis of somataform disorder, substance dependence or abuse disorder, paranoid, passive-aggressive and antisocial personality disorders or traits, and other personality disorders than those

in the comparison group. However, there is no causal link between the primary and secondary conditions. Dubovsky (2008) cautioned of the possibility of misdiagnosis as alcohol-related neurodevelopmental disorders can look like many other mental health diagnoses or developmental disabilities. Making a differential diagnosis for FASD rather than any of the myriad other possibilities is primarily reliant on a history of maternal alcohol use during pregnancy.

▶ **“A differential diagnosis may include conditions that feature growth retardation and facial anomalies, or those that share some cognitive and behavioral signs”**

(Burd, Cotsonas-Hassler, Martsolf & Kerbeshian, 2003, p. 684). Making a differential diagnosis for adults with FAS or pFAS can be done through maternal history of alcohol use during pregnancy, physical examination and chromosome analysis and/or specific molecular testing. A thorough neuropsychological testing is needed for adults with FASD to distinguish FAS or pFAS from other causes for cognitive impairments, such as memory and executive functioning.

In contrast to the disruptive educational experience reported by Streissguth et al., 1997 are the findings of Duquette, Stodel, Fullarton and Hagglund (2006). In a qualitative study



of eight adolescents/young adults (aged 15 to 20), Duquette and colleagues collected information about the subjects' diagnosis and individual characteristics, as well as their school experiences, academic progress, and social connectedness through questionnaires and in-depth interviews. They found that parental expectations of completing high school, support and advocacy directly influenced the individual's persistence in remaining in school.

It has been estimated that 60% of those individuals with a diagnosis of FASD have had difficulties with the law (Boland, Chudley & Grant, 2002; Streissguth, Barr, Kogan & Bookstein, 1997). This strong association may be linked to poor impulse control, hyperactivity, and poor anger and frustration control (BC Partners for Mental Health and Addictions Information, 2003). Fast and Conry (2004), in a review of their previous research regarding youth with FASD and the criminal justice system, reported that there was evidence to suggest young people with FASD are vulnerable to criminal offences (i.e. 23% of the population of youth remanded to a forensic psychiatric unit were diagnosed with FAS or FAE) due to their maladaptive behaviours, such as impulsivity, learning disabilities and poor judgment.

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### 3.5

#### Challenges in Diagnosing Adults

A number of challenges are faced when assessing FASD in adults (Fast & Conry, 2004). First, changes in defining physical characteristics such as distinctive facial features (Spohr, Willms, & Steinhausen, 1993; 1994; 2007). This can be compounded by additional head traumas experienced from violence or accidents to which individuals with FASD may be more susceptible (Fast & Conry, 2004) because of their vulnerabilities. A third challenge is the lack of specificity for many of the behaviours associated with FASD and their potential overlap with other common learning and behavioural disorders, such as Attention Deficit Hyperactivity Disorder (ADHD), learning disabilities, and conduct disorder (Fast & Conry, 2004).

Chudley, Kilgour, Cranston and Edwards (2007) remind us that "only FAS can be diagnosed without information on prenatal alcohol exposure" (p. 263). In individuals with cognitive and behavioural difficulties (but lacking the distinctive facial features and in the absence of fetal alcohol exposure confirmation), an FASD-related diagnosis cannot be easily made. This



is particularly troublesome, when considering adult assessment, as facial dysmorphology may disappear as the person ages (Streissguth, Barr, Kogan & Bookstein, 1997; Streissguth et al., 1991) and records or recollections of maternal alcohol use during pregnancy may not be available (Chudley, Kilgour, Cranston & Edwards, 2007; Fast & Conry, 2004). Informative birth records, which could provide information about the amount of alcohol intake during pregnancy, may not be available or are non-existent. Reliable models of information gathering could assist in diagnosis.

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### 3.6

#### **Follow-Up to FASD Diagnosis**

Through our review of the literature in relation to adults, it is evident that the issue of adult diagnosis is addressed in a limited fashion, that a consistent approach is difficult to identify and the financial infrastructure to support adult diagnosis does not presently exist in the public domain. Private clinics do exist that engage in screening and adult assessment, such as the Asante Centre in British Columbia, Lakeland Centre for FASD, The OBD

Triage Institute and Medigene in Alberta, yet some people seeking diagnosis may not have the financial resources to access services on a fee-for-service basis.

Chudley, Kilgour, Cranston and Edwards (2007) highlighted the importance in the diagnostic process of the multidisciplinary team in making recommendations for a management plan following formal diagnosis. They also stressed that team members need to work with community partners and resources to maximize the intervention potential for each affected individual. This may involve engaging with social service agencies, employers and vocational training professionals, parole officers, guardians and members of support networks, and advocacy workers among others. Despite this complex role for team members, there is a limited capacity at present within the professional communities for people to gain the training and experience to make an FASD-related diagnosis (Chudley et al., 2005).

# 4.0 Conclusions and Implications

■ The purpose of this literature review was to look specifically at the diagnosis and assessment of adults, the challenges, as well as promising techniques and tools used. The following sections will address the strengths and gaps in the literature. Practice, policy and research implications will provide directions for the future.

## 4.1

### Strengths of the Literature

There is a sufficient body of biomedical research that explores the physical and physiological characteristics of individuals, including adults, living with FASD to produce objective, quantifiable measures of the anatomical abnormalities associated with FASD. However, the social science literature exploring the consequences (behavioural, cognitive and psychological) of these physical abnormalities is much more fragmented. A number of key deficit areas have been identified, but there is no consensus in the research or practice literature reviewed about how to measure these developmental and behavioural areas for alcohol-exposed individuals.

## 4.2

### Limitations and Gaps in the Literature

*“I’m seeking an FASD screening tool/functional assessment for adults that will allow our frontline staff the ability to identify the strengths and deficits within their clients. Unfortunately I haven’t run across anything appropriate as of yet.”*

This plea for assistance by an agency worker was received by Dr. Dorothy Badry in July 2008, and represents one of the major gaps in the literature on adult assessment and diagnosis of FASD. There are several promising tools or tools that have been used in a select setting that could, however, be adapted for more general screening situations.

Astley (2003) presented an argument for the need for “an accurate and reproducible method of diagnosis” in children (p. 2). In that argument, she raised a number of points that are as valid





today in terms of the lack of clear and replicable adult diagnostic methods. Astley presented her arguments from three perspectives, and they have been adapted here with adults with FASD in mind. First, from a clinical perspective, the individual who may be misdiagnosed would receive inappropriate intervention and support, and be at increased risk for secondary consequences of FASD. From a public health perspective, true prevalence rates for FASD remain hidden when people remain undiagnosed or are misdiagnosed, which can lead to the thwarting of funds needed to deal adequately with the health care, social and educational needs of adults with FASD. Finally, from a clinical research perspective, inaccurate diagnosis reduces the ability of researchers and users of research to make meaningful comparisons between different groups, and

► **“non-standardized diagnostic methods prevent valid comparisons between studies,”**

which would advance our research knowledge more fully (p. 2). Having a standard diagnostic method (as the 4-Digit Diagnostic Code has been for children) used in the assessment of adults would go a long way in countering these clinical, public health and research deficits.

While there are some suggestions for accurate screening and diagnostic methods based on those that have been successful with children and

adolescents, to date there is no methodology in either screening or diagnostic method that is used across multiple practice or research situations.

There is limited information on the prevalence rates of FASD in adults. This is, in part, because there are no reliable biological markers that readily define those affected, especially with diagnoses other than FAS. Estimates of FAS occurrence vary from 1 to 4.8 per 1,000 live births and approximately 9 per 1,000 live births if all the diagnostic categories for FASD are included (Sampson et al., 1997). This is assumed to under-represent the actual incidence (Sokol, Delaney-Black & Nordstrom, 2008). The variability in rates is, in part, due to the lack of uniformity in what is accepted as the diagnostic criteria for those who lack the dysmorphic features – the high proportion of adults and children with ARND, for example.



### 4.3

#### Implications for Practice

The primary practice implication is the need for the development of consistent best practice models for screening, assessment and diagnosis specific to adults with FASD. With these in place, the identification of this population could then move into the implementation of programs and services that will provide the type and level of support needed by adults living with FASD, to promote optimal functioning and provide a better quality of life than is currently available to many alcohol-exposed people. For example, the World Health Organization Quality of Life scale is a 26-item assessment of quality of 24 life facets. This measure was used by Grant, Huggins, Connor and Streissguth (2005) to assess 11 women with an FASD diagnosis. Their findings indicated these women had a poor quality of life and higher levels of psychiatric distress and behavioural problems compared with other at-risk populations. Grant and colleagues assessed the quality of life scores of the women living with FASD to be similar to those of individuals living with a chronic illness.

It is a challenge to diagnose adults without an existing infrastructure in policy and practice that supports this community need. A focus on diagnosing children with FASD has raised awareness that similar needs exist for adults. One

of the key issues for adults, particularly those from homes where alcoholism was a serious issue, is that retrospective information regarding their own in utero history may not be readily available. Diagnostic guidelines clearly state that

► **“prenatal alcohol exposure requires confirmation of alcohol consumption by the mother”**

(Chudley et al., 2007 , p. S11). Discovering this information requires protocols that are sensitive to adults who have traumatic histories.

Another area that will affect practice is the development of support services specifically for adults living with FASD. These support services will be of increasing importance as more adults are diagnosed with FASD and those diagnosed as children and adolescents age. Stonehocker (2007) prepared an evaluation of an adult support coordinator program associated with the Lakeland Centre for FASD in Cold Lake, Alberta. She assessed client, caregiver, service provider, and systems outcomes. Gaps in services recognized through this evaluation were in the areas of supervised emergency housing, transportation, medical care, supported living, and transition planning to adult services. These issues can be addressed only with significant interaction and awareness with municipal authorities.



Educational programs for various professionals who might be involved in screening and referring adults for complete diagnostic assessment (e.g. primary care physicians and other health care professionals, educators, mental health professionals, social service workers and professionals in the justice system) must be developed. Sharpe et al. (2004) suggested the need to develop FAS regional training centres as well as educational curricula for medical and allied health professionals that incorporate evidence-based diagnostic guidelines for FASD. Increasing training could directly impact an increased capacity for screening, diagnosing and supporting adults living with FASD. This need is supported by a Canadian survey of pediatricians, psychiatrists, obstetricians, midwives and family physicians conducted by Clarke, Tough, Hicks and Clarren (2005). They recognized that “there is a great need to help providers recognize the primary and secondary disabilities of FASD especially in affected individuals who do not have mental retardation or dysmorphic features as part of their diagnosis” (p. 12).

Several training manuals and practical guidelines already exist (e.g. *FAS at Street Level: Fetal Alcohol Spectrum Disorder and Homelessness* (Stade, Clark & D’Agostino, 2004), *Psychosocial Needs Associated with Fetal Alcohol Syndrome: Practical Guidelines for Parents and Caretakers* (Ladue, 1993), *Neurobehaviour in Adolescents and Adults* (FAS Community Resource Center, n.d.), and *Fetal Alcohol Spectrum Disorder: A Learning Module for Health and Social Service*

*Workers* (Capital Health Edmonton and Area, 2005). These could be used and other resources developed to increase awareness of FASD with a focus on the adult population. A secondary issue related to consistency of knowledge/education about FASD is that people have been informed differently through various educational opportunities related to FASD and may apply this knowledge differentially, thus causing inconsistencies in response to FASD.

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#### 4.4

### Implications for Policy

Through our review of the literature in relation to adult diagnosis and assessment, it is evident that the issue of adult diagnosis is addressed in a limited fashion, that a consistent approach is difficult to identify, and that the financial infrastructure to support adult diagnostic clinics and teams do not presently exist in the public domain. Private clinics do exist that engage in adult assessment, such as the Asante Centre in British Columbia, The OBD Triage Institute and Medigene in Alberta, but the cost for the assessment is often in the range of \$1,000 to \$5,000 or more. Some clinics are able to fundraise or use research dollars to support the assessment process and thus do not have to pass the cost along to others. However, if accessible diagnosis is to be available, then more sustainable funding needs to be in place. If the provincial government strategic plans for “timely



diagnosis, assessment and planning for children, youth and adults affected by FASD” (Fryer, 2005, p. 6) is to be fulfilled, then policy must direct that diagnostic services be covered by universal health care rather than left as a cost burden on the individual or his or her family.

This implication echoes and extends to adults the policy recommendation made by Pei and Rinaldi (2004):

- ▶ **“policymakers will need to recognize the extent of the resources required by children with FASD and their families, and provide the financial support necessary for the individualized intervention that is required”**

(p. 135). For adults, the cost of assessment needs first to be financially covered by health care and the services provided to address the post-diagnosis intervention plan.

## 4.5

### Implications for Research

The following highlight several research ideas that need further development if the field of adult assessment and diagnosis of FASD is to advance. First, it would be extremely helpful to have a comprehensive survey of Canadian

clinics and programs where adults are currently being assessed. This could be modelled after the FASD clinical capacity study of Clarren and Lutke (2008) but extend it to assess the capacity of all Canadian regions. Second, the use of the Fetal Alcohol Behavior Scale (36-item FAS/FAE behavioural phenotype) as a screening tool or the development of another tool that is tested in a variety of clinical contexts could lead to a reliable and valid screening instrument with wide clinical application. This is a practice need that further research could help to fulfill.

A third area for further research exploration is that of gender differences in the symptomology and presentation of features of FASD in adults. A gender lens is critical as well as a trauma-informed response that recognizes the history of women who become birth mothers and may have an FASD. This would suggest that specific protocols for screening, assessment and diagnosis are sensitive to gender-based issues. A women-centred approach has been advocated through the FASD Network Action Team on women’s health and is seen as critical to the prevention of further births of children with FASD.

Another research trajectory could involve further investigation into the quality of life experienced by adults with FASD. Research to date has primarily focused on the physical, behavioural and cognitive aspects of this condition. The recognition that FASD impacts adult functioning could be further explored, and the assessment of the quality of life changes from pre- to



post-intervention could serve as a measure of the effectiveness of the intervention strategies used following diagnosis of adults.

Canadian leadership in research as well as practice could be enhanced through Canadian longitudinal studies that determine potential changes over time. International research using longitudinal designs have focused on the physical characteristics and secondary conditions of individuals affected by FAS. The diversity of the Canadian landscape in terms of multicultural populations and rural-urban areas could advance our knowledge in areas such as prevalence rates and diagnostic characteristics reflective of this diversity.

The Canada Northwest FASD Research Network has established five Network Action Teams (NATS), each with a different focus, including diagnosis, clinical intervention for those with FASD, intervention from a women's determinants of health perspective, primary prevention and mentoring.<sup>4</sup>

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4 [www.canfasd.ca/](http://www.canfasd.ca/)

## 4.6

### Conclusions and Recommendations

Through this systematic review of the literature on adult diagnosis of FASD, it is clear that although the infrastructure does not exist within federal/provincial/territorial policy and practice frameworks, the need exists to establish services to address this need. The progress of work over the decades in relation to this topic has been remarkable, and addressing the phenomenon of FASD should be a primary concern in the public domain. Publicity about adults with FASD has often been negative and related to criminal or anti-social behaviour while reports of successful adults are limited. It is natural after the recognition of FAS/FASD in children that the field progress to a similar response for adults. We now recognize that FASD is a lifelong disability, and the need for consistent diagnostic resources, supports and response frameworks would benefit adults who remain undiagnosed. These individuals face their struggles often without knowing the cause of their challenges. They are left attempting to negotiate



a world that does not know how to respond to individuals who “talk better than they do,” as Nathan Ory said in Yellowknife, NWT in 2005.

This review of the literature suggests a strong need for diagnostic resources for adults beyond those that currently exist. Those working with individuals who are alcohol exposed and not yet diagnosed have issued pleas for supports for these adults in conference presentations on FASD, in educational forums on FASD, on Listservs and chat rooms throughout the country and beyond. The voices of caregivers and families with the support of physicians, psychologists, social workers and health professionals have articulated the need for adult resources as knowledge grows about the complexities of FASD across the lifespan.

The implications related to this review in terms of adult diagnosis are that there is a consistent message emerging that such resources are both desired and required in communities and among professionals who engage with alcohol-exposed adults in need of both diagnosis and support. The knowledge garnered to date, which originated from the medical profession and was consequently disseminated to a wide variety of professional bodies for children, is a cornerstone for development of equivalent resources for adults. The justice system in particular has raised this concern as adults with suspected or diagnosed FASD enter their systems. Fast and Conry (2004) have taken up this topic as response models in this system develop. However, case models for practice are slow to develop despite the recognition of this need. As a result of this

systematic review, a body of literature that was surprisingly rich exists, and a consistent response is coherent in terms of the need to establish in both policy and practice an adult diagnostic framework.

FASD is a human issue: it impacts the lives of individuals, families and communities. There are consequences in not recognizing FASD in individuals, including adults. These consequences include having individuals live in multiple living arrangements such as foster care and may contribute to becoming homeless or incarcerated (Chudley, Kilgour, Cranston & Edwards, 2007; Clarke, Tough, Hicks & Clarren, 2005; Dubovsky, 2008; Famy, Streissguth & Unis, 1998; Lemoine, 2003). Another consequence can be the inappropriate use of resources and approaches in treating individuals when FASD has not been recognized (Dubovsky, 2008). Employment and parenting difficulties may also plague adults who remain undiagnosed (Dubovsky, 2008; Famy, Streissguth & Unis, 1998). Suicide is also a very real possibility for adults and adolescents with FASD, especially if it remains undiagnosed (O'Malley & Huggins, 2005). The need to enhance the capabilities of assessment teams and centres to accurately assess and diagnose adults who potentially have some form of an FASD is a pressing problem in Canada and internationally.

Key strategies for intervention with adults diagnosed with FASD are emerging within the Canadian experience. First, there is a need to include trauma-informed practices with adults living with FASD, which implies the need for



screening and diagnostic protocols that are sensitive to the needs of individuals. Second, the need exists for a greater understanding and careful assessment of addictions and substance abuse issues for undiagnosed adults. Third, ongoing knowledge development of adult-specific responses, particularly related to neurocognitive and neurobehavioural disorders, is needed. Understanding how adults with FASD process auditory information, for example, is a key point to develop better practice and offer a consistent framework of response across each province and territory. Accurate and effective diagnosis and intervention fosters healthier individuals, families and communities. Another key strategy would be to provide opportunities and the ability for adults with FASD to negotiate required supports in different systems. It is important that those working in the field with children, adolescents and adults with FASD become informed about the complexity of this disabling condition and develop models and frameworks of a complex case management response through the better use of case studies as learning opportunities. Knowledge exchange among different professions working in this area is another strategy that would provide a deeper understanding of the complexity of this disabling condition. For example, social workers need to know more about how to meaningfully interpret psychological evaluations while other professionals would benefit from a clearer understanding of the psychosocial implications of living with an FASD. This exchange would be helpful in advancing the knowledge base related to FASD if each of the disciplines involved leads to

a better understanding of each other's roles in the screening, assessment and diagnosis of FASD and a better informed professional response system. Additionally, it is important to strengthen the linkages between frontline workers and those engaged in diagnosis. Although adult diagnosis does occur in a fashion, there is a generalized perception that this is a service not available in Canada. Finally, strong advocates have emerged on the Canadian landscape to recommend adult diagnosis – Lutke, Clarren, Lawryk, McFarlane, Riley, and Ory for example. Let us build on their expertise and develop the next generation of researchers and practitioners who are knowledgeable about and sensitive to the experiences of adults living with FASD.

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# Appendix A: FAS screening form

Source: Burd, Cox, Fjelstad, & McCulloch, 1999 as presented in Burd et al. (2003, p. 687)

Name \_\_\_\_\_ DOB \_\_\_\_/\_\_\_\_/\_\_\_\_ Age \_\_\_\_ Sex (circle one) F M

Date of Exam \_\_\_\_/\_\_\_\_/\_\_\_\_

Child's Race (circle one) 1) white 2) NA 3) other

Height \_\_\_\_\_ inches <5% Y \_\_\_\_ N \_\_\_\_ 10

Weight \_\_\_\_\_ pounds <5% Y \_\_\_\_ N \_\_\_\_ 10

Head Cir. \_\_\_\_\_ cm <5% Y \_\_\_\_ N \_\_\_\_ 10

<b>Head and face</b>	<b>Ears stick out (protruding auricles)</b>	Y____ N____ 4
	<b>Skin folds near inner eye (epicanthal folds)</b>	Y____ N____ 5
	<b>Drooping of eyelids (ptosis)</b>	Y____ N____ 4
	<b>Crossed eyes – one or both eyes (strabismus)</b>	Y____ N____ 3
	<b>Flat midface/cheeks (hypoplastic macila)</b>	Y____ N____ 7
	<b>Flat/low nose between eyes (low nasal bridge)</b>	Y____ N____ 2
	<b>Upturned nose</b>	Y____ N____ 5
	<b>Groove between lip and nose absent or shallow (flat philtrum)</b>	Y____ N____ 5
	<b>Thin upper lip</b>	Y____ N____ 4
	<b>Cleft lip or cleft of roof of mouth (present or repaired)</b>	Y____ N____ 4
<b>Neck and back</b>	<b>Short, broad neck</b>	Y____ N____ 4
	<b>Curvature of the spine (scoliosis)</b>	Y____ N____ 1
	<b>Spina bifida (history of neural tube defect)</b>	Y____ N____



<b>Arms and hands</b>	<b>Fingers, elbows (limited joint mobility)</b>	Y___ N___ 4
	<b>Permanently curved, small fingers, especially pinkies (clinomicrodactyly)</b>	Y___ N___ 1
	<b>Deep or accentuated palmar crease</b>	Y___ N___ 4
	<b>Small nails/nail beds (hypoplastic nails)</b>	Y___ N___ 1
	<b>Tremulous, poor finger agility (fine motor dysfunction)</b>	Y___ N___ 1
<b>Chest</b>	<b>Sunken chest (pectus excavatum)</b>	Y___ N___ 3
	<b>Chest sticks out (pectus carinatum)</b>	Y___ N___ 1
	<b>History of heart murmur or any heart defect</b>	Y___ N___ 4
<b>Skin</b>	<b>Raised red birthmarks (capillary hemangiomas)</b>	Y___ N___ 4
	<b>Greater than normal body hair, hair also on forehead and back (hirsutism)</b>	Y___ N___ 1
<b>Development</b>	<b>Mild to moderate mental retardation (&lt; 70)</b>	Y___ N___ 10
	<b>Speech and language delays</b>	Y___ N___ 2
	<b>Hearing problems</b>	Y___ N___ 1
	<b>Vision problems</b>	Y___ N___ 1
	<b>Attention concentration problems</b>	Y___ N___ 2
	<b>Hyperactivity</b>	Y___ N___ 5

Comments: \_\_\_\_\_

Score total \_\_\_\_\_

Refer if 20 or above

# Appendix B: Evaluation and management of frontal lobe functions

Source: Grafman, & Litvan (1999, p. 1922)

## Evaluation and management of frontal lobe functions

Prefrontal cortical area	Cognitive domain	Neurobehavioral probe* (always compared with premorbid behavior)	Management
Ventromedial	Social skills	Does the patient make inappropriate sexual remarks, eat excessively, or disobey other types of social rules of behavior?	Pharmacological agents; behavioural management
	Inhibition of prepotent responses	Does the patient exhibit stereotyped behaviors such as repeating the same phrase or activities over and over again?	Pharmacological agents; behavioural management
	Motivation and reward	Does the patient still enjoy the same activities or items that they used to?	Pharmacological agents; behavioural management
Medial	Allocation of attention	Is the patient's concentration distracted by irrelevant sounds or sights in the environment?	Environmental control: Pharmacological agents?
	Predictive planning	Can the patient do routine activities, such as using an automatic bank teller or using a tea kettle to make a cup of tea?	Environmental control
Frontopolar	Adaptive planning	Can the patient be interrupted in the middle of a conversation to answer the telephone and then after hanging up the telephone appropriately resume the conversation without cueing?	Environmental control



<b>Prefrontal cortical area</b>	<b>Cognitive domain</b>	<b>Neurobehavioral probe* (always compared with premorbid behavior)</b>	<b>Management</b>
<b>Dorsolateral</b>	<b>Rehearsing short-term plans</b>	<b>Can the patient remember a telephone number after a very brief pause?</b>	<b>Cognitive strategies</b>
	<b>Reasoning</b>	<b>Can the patient explain how two objects are similar (e.g. table and chair are both furniture), deduce an answer to a mystery, or adjust to an unforeseen demand or event?</b>	<b>Cognitive strategies</b>
	<b>Thematic understanding</b>	<b>Can the patient read a short article or watch a brief television programme and get the point or theme of what they read or watched?</b>	<b>Cognitive strategies</b>

\* If screening identified potential areas of impairment, specialized testing by a neuropsychologist, neuropsychiatrist, or behavioral neurologist is usually required.

# Appendix C: Multidisciplinary Team Roles

Source: Fryer (2008, p. 9)

## Occupational Therapy

- Screens for fine motor, gross motor and sensory processing as well as visual motor skills**
- Conducts the QNST – soft neurological screening**
- Provides recommendations in areas of expertise including emotional regulation and calming activities**

## Social Worker

- Coordinates the team**
- Arranges for assessments (space, time and team)**
- Collects needed information for team assessment from multiple sources**
- Contacts and prepares and supports the child and their family**
- Writes final report integrating the contributions from each team member**
- Admin support to clinic day (food, coffee, other tasks)**
- Helping families with transportation needs (parking passes, getting to the clinic)**

## Physician

- Provides diagnosis in the medial context**
- Recognizes additional risk factors, conducts a physical examination**
- Provides differential diagnosis**



### Speech Language Pathologist

**Provides screening level assessment for language issues**

### Neuropsychology

**Assesses the level of brain damage by testing the cognitive function (intellectual, academic, and executive); adaptive and behavioral/social domains**

### Family Support Worker

**This position reports to the FASD Community Circle, and does not have a role in the diagnostic process. Consent from the legal guardian is obtained prior to involvement in the diagnostic and information-sharing process.**

**Informs herself on the issues and needs of the child and family by attending the assessment and diagnostic clinic days.**

**Explores needs with families based on their requests, in the area of school system, social groups and ongoing education for both the child and the parent(s).**

**Provides education to those in the child's community to reframe their approach to the child.**

# Appendix D: Pre-Assessment Checklist

Source: Dewane, Scott, & Brems (2005, p. 46)

## Referral process:

- Receive referrals through a single point of entry system
- Utilize a standardized referral form
- Provide client or caregiver with a letter explaining purpose and process of diagnostic team

## Screening process:

- Determine eligibility of client
- Prioritize client list
- Inform referral sources in a timely manner of outcome of screening process
- Provide an explanation and referral alternatives to ineligible clients

## Forms completion:

- Schedule a face-to-face appointment with client and caregivers
- Assist clients with forms completion to decrease attrition rate
- Use the Paper Trail notebook
- Utilize a pre-established charting system
- Track client status through an internal electronic tracking system

## Obtaining records:

- Secure signed release of information forms
- Use telephone, fax, or mail for making request
- Learn the most effective way to request records from different facilities
- Remember that gathering information from other agencies will improve the diagnostic



# Appendix E: FAS Diagnostic Checklist

Source: Burd & Martsolf (1989, p. 40)

Severity score for FAS and related disorders

<b>1. Growth</b>	
Height	= 10 – height percentile
Weight	= 10 – weight percentile
Head circumference	= 10 – head circumference percentile
<b>2. Facial Features</b>	
Number of facial features	1 point for each
Number of anomalies	1 point for each
<b>3. Neuropsychological</b>	
Comorbid neuropsychiatric conditions	2 points for each
IQ	<85 = 4 points <70 = 8 points <50 = 10 points
<b>4. Neurobehavioural</b>	
Sleep	<6 = 1 point
(consecutive hours, select only one)	<4 = 5 points <2 = 10 points



<b>5. Vineland scores</b>		
<b>10 – communication score</b>	<b>+ 10</b>	
<b>10 – daily living score</b>	<b>+ 10</b>	
<b>10 – socialization score</b>	<b>+ 10</b>	
<b>10 – motor skills score</b>	<b>+ 10</b>	
<b>6. Services</b>		
<b>Foster care placement</b>	<b>3 points each</b>	
<b>Inpatient hospital care</b>	<b>1 point each</b>	
<b>Criminal justice</b>	<b>1 point each month probation/ incarceration</b>	
<b>Special education</b>	<b>1 point each hour of service per day</b>	
<b>Residential care</b>	<b>1 point each month in the last year</b>	
<b>FAS Phenotype Score</b>	<b>1 + 2 + 3</b>	
<b>FAE Phenotype Score</b>	<b>3 + 4 + 5 + 6</b>	
<b>Total Score</b>		



**Inventory of Literature on the  
Assessment and Diagnosis of FASD  
Among Adults**

