Section 9:

Fetal Alcohol Spectrum Disorders and the Justice System

By Rae Mitten

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TABLE OF CONTENTS

LIST OF ABBREVIATIONS i

I. INTRODUCTION 1

1.1 Need for Community-Based Treatment for FASDs 1

1.2 Cost-Benefit Discussion 2

1.3 Need for Therapeutic, FASD Courts 3

1.4 Historical Context of Marginalization 4

2. FETAL ALCOHOL SPECTRUM DISORDERS 5

2.1 Introduction 5

2.2 Cause of FASDs 6

2.3 Incidence 7

2.4 Characteristics of FASDs 10

2.4.1 Primary Characteristics 10

2.4.2. Secondary Characteristics 11

3. PREVENTION 12

3.1 Primary Prevention 12

3.2 Secondary Prevention 15

3.3 Tertiary Prevention 16

3.4 Prevention of secondary disabilities 17

4. SOCIAL CONSTRUCTION OF FASD AND ITS IMPLICATIONS 20

5. RIGHTS DISCOURSE 23

5.1 Section 15 of the *Charter of Rights and Freedoms*: Equality 23

5.2 The Law Analysis: Context and Dignity 23

5.3 Crown Justification Under Section 1 of the *Charter* 25

5.4 Jurisdiction over Health Care 26

5.5 Section 7 of the *Charter*: Right to life, liberty and security of person 27

6. CONCLUSION 29

REFERENCES 30

LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactive Disorder
ARBD	Alcohol Related Birth Defects
ARND	Alcohol Related Neurological Disorder
ASD	Autism Spectrum Disorder
ASDs	Autism Spectrum Disorders
BAC	Blood Alcohol Content
BTC	Breaking the Cycle
CALJ	Canadian Association of Liquor Jurisdictions
CAUT	Canadian Association of University Teachers
CBA	Canada Brewers' Association
CNS	Central Nervous System
DPN	Diagnostic and Prevention Network, Washington State
DSM-IV	*Diagnostic and Statistical Manual of Mental Disorders, Volume IV*
FACE	Fetal Alcohol Canada Expertise
FAE	Fetal Alcohol Effects
FAEE	Fatty Acid Ethyl Esters
FAS	Fetal Alcohol Syndrome
FAS/E	Fetal Alcohol Syndrome and/or Fetal Alcohol Effects
FASD	Fetal Alcohol Spectrum Disorder
FASDs	Fetal Alcohol Spectrum Disorders

IBI	Intensive Behavioral Intervention
ICD	International Classification of Disease
ICFS	Indian Child and Family Services
LAT	Lovaas Autism Treatment
MD	Medical Doctor
NCR	Not Criminally Responsible
NIAAA	National Institute on Alcohol Abuse and Alcoholism (U.S.)
OT	Occupational Therapist
P-CAP	Parent-Child Assistance Program
PEER	Parents as Early Educational Resource
pFAS	Partial Fetal Alcohol Syndrome
PT	Physical Therapist
RCI	Restorative Circles Initiative
SLGA	Saskatchewan Liquor and Gaming Authority
SLP	Speech-language Pathologist
IOM	Institute of Medicine (U.S.)
UST	Unfit to Stand Trial
WHO	World Health Organization
YCJA	*Youth Criminal Justice Act*
YOA	*Young Offenders Act*

FETAL ALCOHOL SPECTRUM DISORDERS (FASDs) AND THE JUSTICE SYSTEM

By Rae Mitten[1]

I. INTRODUCTION

1.1 Need for Community-Based Treatment for Individuals with FASD

Fetal alcohol spectrum disorders (FASDs) are a continuum of conditions, from mild to severe, that result from prenatal exposure to alcohol.[2] The thrust of this analysis is that for fetal alcohol offenders, holistic, community-based treatment is preferable as a sentencing option to incarceration. This contention is supported by an understanding of the nature of the syndrome per se. Because of reduced ability to think abstractly due to damage that alcohol inflicted on their developing brains *in utero*, fetal alcohol affected individuals do not understand well cause/effect relationships, including appreciation of the consequences of their actions, nor are they able to generalize completely what they learn in one situation to another.[3] Moreover, their judgment is poor, and they are influenced easily by others.[4] Although they may function fairly well in a structured, carceral environment, useful coping skills learned there are not readily transferable to noncarceral settings and must be largely relearned on the outside.[5] Because of impulsivity and obliviousness or blindness to consequences, fetal alcohol offenders are liable upon release to reoffend regardless of length of incarceration, making recidivism rates high for this population.[6] The sentencing principle of deterrence does not function well for individuals whose ability to appreciate consequences is limited.[7] Statistics demonstrate disproportionately high rates of incarceration of Aboriginal people,[8] with fetal alcohol conditions a concomitant factor.[9]

It should be clarified that fetal alcohol is not solely an Aboriginal, but a global phenomenon, found particularly where populations have been subjected to damaging effects of colonization or globalization, and resultant poverty.[10] Significantly, individuals with fetal alcohol conditions are highly susceptible to negative peer

[1] The author recently completed her LL.M., the topic of her thesis being *Barriers to Implementing Holistic, Community-Based Treatment for Offenders with Fetal Alcohol Conditions*. Much content of the present paper derives from the LL.M. thesis, although there is significant new material, as well.

[2] A more detailed analysis of FASDs occurs in Section 2 of this paper.

[3] *R.* v. *Steeves*, [1998] B.C.J. No. 3151 (BC Prov. Ct.) at para 12-15, expert witness testimony of Dr. Diane Fast, cited in *R.* v. *M.L.*, [2000] S.J. No. l7 at para. 34.

[4] *Ibid*. at para. 15 (Steeves).

[5] *R. v. M.(B.)*, [2003] SKPC 83 (Sask. Prov. Youth Ct.) at para. 43-44, citing A. P. Streissguth, A.P., *Fetal Alcohol Syndrome: A Guide for Families and Communities* (Toronto: Brookes Publishing, 1997) at 238-243.

[6] Conry J. and Fast, D. *Fetal Alcohol Syndrome and the Criminal Justice System* (BC Fetal Alcohol Syndrome Resource Society: Vancouver, c2000) at 104.

[7] *R.* v. *M.L*, [2000] S.J. No. 17 (Sask. Youth Ct.), at para.46b.

[8] Canada Centre for Justice Statistics, Aboriginal Peoples in Canada, retrieved July 30, 2003, from the World Wide Web: http://www.statcan.ca/english/freepub/85F0033MIE/85F0033MIE01001.pdf.

[9] *Supra* note 3, at 2 (*Steeves & M.L.*) citing Streissguth et al's (1996) longitudinal American study of fetal alcohol affected youth, which found that 60% of the cohort aged 12 years or older had experienced trouble with the law; National Institute on Alcohol Abuse and Alcoholism (NIAAA), "Strategic Plan to Address Health Disparities," (Bethseda, Maryland: Feb. 8, 2001): "Children with FAS often develop behavior problems that increase their risk of becoming involved with the Criminal Justice System."

[10] Tait, C. L., Aboriginal Health Research Team, National Network of Aboriginal Mental Health Research, "Fetal Alcohol Syndrome among Canadian Aboriginal Peoples: Review and Analysis of the Intergenerational Links to Residential Schools," (Montreal, Quebec: Aboriginal Healing Foundation, 2002), at 113-117; and Gibson, F. *Home is My Road* (Toronto: Playwrights Canada Press: 2003). First produced in 2003 at Toronto's Factory Theatre Mainspace, April 12 to May 11, 2003, and discussion on a CBC radio interview with author, Florence Gibson, April 15, 2003, 10:00 p.m. on "Between the Covers".

influences which carceral situations present, as well as being, vulnerable to victimization.[11] Such factors render carceral situations, artificial settings removed from the natural world, inappropriate for them.

1.2 Cost-Benefit Discussion

In comparing carceral and community-based options, there is a cost factor to consider. Keeping one youth out of a correctional facility saves $46,000 per year; and keeping one child out of foster care saves $16,000 per year. A child with fetal alcohol syndrome costs conservatively an estimated $1.5 million over his/her lifetime.[12] More liberal estimates put this figure at $5 million.[13] Cost of prenatal to age three intervention programs, such as the Manitoba "Stop FAS Program," is but $3400 per family.[14] On the bases of cost factors and previous discussion, one can tentatively conclude that not only are community-based intervention programs less costly, they are also likely to be more effective in terms of their outcomes, than are carceral options. Therefore, it cannot be deemed reasonable, from a cost-benefit analysis, to persist with the status quo.

Madam Justice Saunders in *Auton v. British Columbia (Attorney General)*[15] was skeptical of formal cost-benefit analyses, considering accurate forecasting of future costs questionable, but nevertheless deemed it obvious that a community-based early intervention program for children suffering from autism, at a current cost of $45,000 to $60,000 annually per child,[16] would be less costly than the alternative of possible life-long institutionalization.

> In a broad sense, it is apparent that the costs incurred in paying for effective treatment of autism may well be more than offset by the savings achieved by assisting autistic children to develop their educational and societal potential rather than dooming them to a life of isolation and institutionalization. [17]

Similar, but more pressing reasoning, applies to individuals with fetal alcohol conditions and their need for community-based treatment in lieu of institutionalization, in view of the incarceration such individuals often face.

Although it is accepted that community-based intervention generally is considered more effective than incarceration by experts in the field, there is a gap in the research related to the relative effectiveness of particular community-based interventions.[18] What works best, and how to implement such effective interventions for individuals with fetal alcohol conditions is not determined completely. Appropriate interventions per se are prospective topics of future qualitative study.[19] The present paper culminates in an analysis of potential avenues to mandate such treatment through the courts, or alternatively, or in addition, through the avenue of policy reform. Only when community-based treatments become more in evidence can problems of those affected by alcohol prenatally be effectively addressed.

[11] *Supra* note 6 at 69-71(Conry & Fast); and *United States* v. *Lee*, 1998 U.S. App. LEXIS 5967, No. 97-2830, United States Court of Appeals for the Eighth Circuit. In *Lee,* a "vulnerable-victim enhancement to sentence" was applied to an offender who plead guilty to sexually abusing a minor. The offender "knew or should have know that the victim of the offense was unusually vulnerable due to … mental condition," pursuant to *U.S. Sentencing Guidelines Manual* 3A1.1(b)(1997). The victim of the sexual abuse had fetal alcohol syndrome and was unusually vulnerable for her age. The offender was sentenced to 21 months imprisonment and two years supervised release, which was affirmed on appeal.

[12] Streissguth, A. P., Aase, J.M., Clarren, S.K., Randels, S.P., LaDue, R.A. and Smith, D.F. "Fetal Alcohol Syndrome in Adolescents and Adults." (1991) 165 JAMA, 1961-1967.

[13] Kellerman, Chris. (2000) *The Five Million Dollar Baby: The Economics of FAS*. Retrieved from the World Wide Web on January 19, 2004: http://www.acbr.com/fas; and McLean, Candis. (2000). *The Fetal Alcohol Crisis*. Retrieved from the World Wide Web on January 19, 2004: http://www.come-over.to/FAS/crisis.

[14] Ridd, D., Manitoba Health, *Pregnant Addicted Women: Manitoba's Experience,* "'Stop FAS: Cost Savings" (Third Annual Face Roundtable, *FAS: When the Children Grow Up,* Sept. 9, 2002, accessed September 30, 2002, http://www.knowtv.com).

[15] [2002] BCCA 538 at para. 145. (*Auton)*.

[16] *Ibid*. at para. 17.

[17] *Ibid*. at para. 147.

[18] Streissguth, A. P. *Fetal Alcohol Syndrome, A Guide for Families and Communities* (Toronto: Brookes Publishing Co., 2001), at 279.

[19] The present author is commencing a Ph.D. study, entitled, *Qualitative Research Involving Community-Based Treatment for Individuals with Fetal Alcohol Spectrum Disorder and its Efficacy.*

1.3 Need for Therapeutic, FASD Courts

Along with the necessity for community-based treatment and sentences, lies the need for therapeutic courts. All members of the court, judge, defense attorney, prosecutor, youth worker, and expert witnesses (including peace officers), need to be informed about fetal alcohol conditions, and the implications of these conditions on various court processes,[20] including fashioning of truly therapeutic conditions:

> Youth workers, lawyers and judges need to be alert to these issues and to canvass and address them—joint submissions for a quick sentence which skirt over such matters risk missing the reasons for offending which can assist to explore alternatives to break the cycle of crime for a youth. As Drs. Conry and Fast suggest in their text Fetal Alcohol Syndrome and the Criminal Justice System (B.C. Law Foundation, 2000) at p. 4:
>
> When judges and lawyers understand the disabilities associated with FAS/FAE, they may be the first to suspect the possibility of this diagnosis in a victim, witness, or accused. Lawyers have an important role to play in presenting the evidence to the court so that people with FAS/FAE are treated fairly. Judges need to understand FAS/FAE and how it may affect sentencing. Others in the legal and correctional systems need to understand the importance of this diagnosis as they come in contact with many offenders with FAS/FAE. The disabilities involved may be subtle or severe.[21]

In addition, a risk assessment instrument specific to individuals with the behavioral and cognitive impairments that those with fetal alcohol conditions possess, and cognizant of supports available that would reduce risk, is essential,[22] as conventional risk assessment devices are designed primarily for offenders without cognitive impairments. Otherwise, any initial mitigating effect of mental disorder in sentencing considerations, may be converted to an aggravating factor when risk of re-offence is considered. In addition, risk assessment is to take into consideration any ameliorative effect on risk of therapeutic dispositions tailored by the court for the offender in his sentence order.[23]

Young persons affected by FASD usually have limited social and mental skills which reduce the effectiveness of punishment, and lead them to impulsively repeat property and system-generated offences:

> Saskatchewan must focus on this issue due to having the highest youth custody rate in Canada, and the highest proportion of persons under the age of 14 in custody. The province also has the highest Aboriginal population and a large segment of that population is children. . . . At one point she [Jo Nanson, a psychologist with a specialty in neuropsychology and expert witness for the court] estimated roughly 50% of the youth we see in youth court have some form of FASD. [24]

FASD youth require a productive pro-social environment; however it is difficult for courts to implement provisions in *Youth Criminal Justice Act*[25] that would address such needs of FASDs, due to lack of resources in the community,[26] contributing to a continual cycling of disabled offenders through the system in assembly-line fashion, without stopping and asking why they are offending, and what supports they need.[27]

[20] *Supra* note 6. Refer to Conry, J. and Fast, D.K. *Fetal Alcohol Syndrome and the Criminal Justice System* (Vancouver: Law Foundation of British Columbia, 2000), for a discussion of these factors.

[21] *Supra* note 5, at para. 5. (*R. v. M.(B.)*)

[22] *R.*. v. *Proulx*, [2001] 1 S.C.R. 61 at 69-72. Lamer C.J. held that dangerousness is to be assessed in reference to the risk of re-offence and the gravity of damage that could thus ensure. However, the risk of reoffence should be assessed in the light of the conditions tailored for the sentence. The risk of reoffending with therapeutic supports in place is often considerably lessened.

[23] *Ibid.* (*Proulx*).

[24] Driver, D. "Saskatchewan judges lead fight for handling of FASD victims, " quoting Judge Turpel-Lafond and Judge Whelan, 23(11) *The Lawyers Weekly*, July 11, 2003.

[25] S.C. 2002, c.1 (royal assent February 19, 2002, came into force April 1, 2003).

[26] *Supra* note 5 at para 94-96 (*R.. v. M.(B.)*); and *R. v. M.(B.)#2*, [2003] SKPC 133 at para. 6, 22, 15 and 18.

[27] Supra note 24, quoting Judge Turpel-Lafond. (Driver, D., "Saskatchewan judges lead fight for handling of FASD victims")

1.4 Historical Context of Marginalization

Although colonization begins with European Contact, continuing through, *inter alia*, the fur trade, whiskey trade, small pox pandemic, and near extinction of the buffalo, marginalization of the Indian way of life in Saskatchewan culminated in the decades after 1885. Confinement of Indians to reserves accelerated, following the Metis Resistance at Batoche, the trial and execution at Regina of Louis Riel, the trials and executions at Battleford of eight Indians, and the arrest and confinement of Poundmaker and Big Bear.[28] Implementation of the numbered treaties stalled; instead, Indians were made subject to the paternalistic *Indian Act*, which had been enacted first in 1876.[29] Indian Bands were created and white Indian Agents appointed to administer reserves.[30] Amendments to the *Indian Act* in 1884,[31] the so-called "anti-potlatch laws" forbade many Indian ceremonies for nearly seventy years, a prohibition ending only in 1951.[32] Other repressive measures enacted included: prohibition of raising money or of retaining a lawyer to advance land claims;[33] the "pass" laws whereby Indians required the permission of the Indian Agent to leave a reserve for any reason;[34] an interdict on producing or selling goods without the permission of the Indian agent;[35] and loss of status and entitlements for receiving a university education,[36] or, for a woman, marrying a non-Indian[37] (the latter not repealed until Bill C-31 in 1985[38]). In addition, Indians, considered not to be citizens, but rather wards of the Crown, were not allowed to vote in Federal elections until 1960.[39] Prior to the 1960 enactment, they were subject to losing their tax exemption as Indians if they voted.[40] In 1970, federal government prohibitions against use of alcohol by Indians were repealed.[41] Such externally imposed prohibitions may have contributed to the binge pattern of drinking characteristic of Aboriginal peoples. Binge drinking quickly raises the blood alcohol concentration (BAC), accelerating the teratogenic effects of alcohol. The unborn's BAC does not dissipate, as the fetal liver is not functioning to metabolize alcohol; therefore, alcohol remains in the fetal system much longer than it remains in the mother's system, with concomitant increased damage to the fetus.[42]

The interplay of the intergenerational effects of alcohol and the treaty provisions continue today, and await full resolution. Aboriginal alcohol consumption patterns continue largely unchanged from their origins during the whiskey trade.[43] Adverse effects on health, accidents, mortality, including suicide, family breakdown, poverty, unemployment, and alcohol teratogenicity such as fetal alcohol conditions are the result.[44] Since colonization, Aboriginal women have been particularly deleteriously affected by restrictive and sexist legislation and policy, which has tended to differentially exclude them from status, band membership and governance, and

[28] Beal, B. and Macleod, R. *Prairie Fire, The 1885 North-West Rebellion* (Toronto: McClelland & Stewart Inc., 1994.

[29] *Indian Act*, S.C., 1876, c.18.

[30] *Ibid*. at s. 4 and s. 3(11).

[31] *An Act further to amend "The Indian Act, 1880."* S.C. 1884, c. 27, s. 3.

[32] *Indian Act*. S.C. 1951, c. 29, s. 123.

[33] *Indian Act*, R.S.C. 1906, c. 81, s. 149A [en. S.C. 1926-27, c.32, s. 6].

[34] Canada, *Report of the Royal Commission on Aboriginal Peoples*, *Looking Forward, Looking Back*, **vol. 1**, "9.10 Pass System," (Ottawa: The Commission, c1996) at 296, citing F. L. Barron, "The Indian Pass System in the Canadian West, 1882-1935," 13 *Prairie Forum* no. 1 (Spring, 1988), p. 27-28. Although the pass system was official policy, there was never any legislative basis for it. It is said to have arisen from a suggestion by the Deputy Superintendent of Indian Affairs to Prime Minister MacDonald in 1886, although Barron believes that it originated with Hayter Reed, former Indian agent at Battleford, at the time he was elevated to Assistant Indian Commissioner. The pass system was a form of local administrative tyranny, according to Barron. Parallels have been made between the Apartheid system in South Africa and the pass system in Canada, although Barron states that the pass system became only a weak reflection of the former: "[It] was applied selectively, but never enjoyed the coercive power and public legitimization conferred by official state sanction" (at p. 39). An early variant of the pass system begin in 1885 during the final days of the Riel Resistance, and there is evidence of it continuing until 1930 is some areas.

[35] *Indian Act*. R.S.C. 1927, c. 98, s. 40 and 41.

[36] *Supra* note 29, s. 86(1). (1876)

[37] *Supra* note 35, s. 14. (1927)

[38] *Indian Act*, R.S.C., 1985, c. I-5, s. 6(1)(c) [en. R.S.C., 1985, c. 32 (lst Supp.) s. 4].

[39] *Canada Elections Act*, S.C., 1960, c. 39, s. 14.

[40] *Indian Act,* R.S.C., 1952, c. 23, s. 14(2)(e). Veterans were exempted from this harsh disqualification.

[41] *Indian Act*. R.S.C. 1970, c.I-6, s. 96 and 98.

[42] *Supra* note 18 at 72-78. (Streissguth, A., 2001, A Guide to Families...)

[43] 1996 NWT Alcohol and Drug Survey, NWT Bureau of Statistics, retrieved February 10, 2003 from the World Wide Web: http://www.stats.gov.nt.ca/SWtatinfo/Health/alcdrug/report.html.

[44] Health Canada, *A Statistical Profile on the Health of First Nations in Canada* (Ottawa, Canada: 2003), retrieved January 30, 2003, from the World Wide Web: http://www.hc-sc.gc.ca/fnihb/sppa/hia/publications/statistical_profile.htm.

concomitant benefits.[45] As well, interference with the exercise of their maternal function came through residential schools and child protection policies. Such devaluation rendered them subject to domestic violence at home and to racism and sexism in the larger community, leaving them traumatized and vulnerable to alcohol abuse and addictions.[46] Prevention, addressed in treaty times through the alcohol ban, continuing currently, through persuasive initiatives such as education about responsible alcohol use, and treatment of addictions cognizant of factors which lead women to addictions, is part of the solution. Resolution of the problems of those involuntarily affected in utero needs to be addressed through the establishment of multidisciplinary, community-based treatment.

2 FETAL ALCOHOL SPECTRUM DISORDERS

2.1 Introduction

Fetal alcohol syndrome was first described in the medical literature in France.[47] Subsequently, a landmark report published in the United States, described a constellation of birth defects in children born to alcoholic women.[48] It has since been described in most countries of the world. A cluster of abnormalities characterize fetal alcohol syndrome (FAS), including dysmorphology of facial features, reduced size in the newborn, as well as more serious problems previously noted in Section 1.1 in the areas of behavior and cognition.

Since the publications by Lemoine,[49] and by Jones and Smith,[50] much interest has developed in teratology, the study of the effects of chemical exposure on the developing fetus. Alcohol is one of a number of chemicals toxic to the developing central nervous system (CNS), which, like mercury, produce malformations in the CNS, along with neurobehavioral dysfunction. Alcohol, a potent teratogen compared to common abusive substances such as heroin, cocaine or marijuana, produces the most serious neurobehavioral effects in the developing fetus. In fact, results attributed to these other substances may be due to concurrent use of alcohol. However, like most teratogens, alcohol does not cause significant damage in 100% of fetuses exposed. Lack of definitive research results regarding effects of low to moderate exposure to alcohol, or from genetic protective factors that some fetuses may possess, should not be interpreted as contradictory to categorical warnings such as that of the Surgeon General of the United States:

> **Warning Label on Alcoholic Beverages. GOVERNMENT WARNING:** (1)ACCORDING TO THE SURGEON GENERAL, WOMEN SHOULD NOT DRINK ALCOHOLIC BEVERAGE DURING PREGNANCY BECAUSE OF THE RISK OF BIRTH DEFECTS. (2) CONSUMPTION OR ALCOHOLIC BEVERAGES IMPAIRS YOUR ABILITY TO DRIVE A CAR OR OPERATE MACHINERY AND MAY CAUSE HEALTH PROBLEMS.[51]

The U.S. warning label is remarkable for clarity and wide distribution.

Health Canada and the Canadian Pediatric Society (supported by nineteen national associations representing medical, nursing and midwifery disciplines, Aboriginal and multicultural groups, and other organizations known for their extensive work in the area of FAS) issued the following joint warning in a news release, October 16, 1996:

[45] Canada, *Report of the Royal Commission on Aboriginal Peoples: Perspectives and Realities,* **vol. 4**, "Chapter 2: Women's Perspectives," (Ottawa: Supply and Services Canada, 1996) at 21-53.

[46] *Ibid*. at 62-71; and retrieved October 25, 2003, from the World Wide Web: http://www.pwhce.ca/sharing.htm.

[47] Lemoine, P, Harouseau H., Borteryu, J., & Menuet J. "Les enfants des parents alcooliques: Anomalies observee apropros de 127 cas. Ouest Medical, 1968: 21: 476-482.

[48] Jones, K.L. & Smith, D.W., "Recognition of Fetal Alcohol Syndrome in Early Infancy," (1973) Lancet, 2: 999-1001

[49] *Supra* note 47. (Lemoine)

[50] *Supra* note 48. (Jones & Smith)

[51] *Public Law*, 100-690, Section 204.

> As there is no definitive information regarding a safe quantity of alcohol use during pregnancy, the Statement's recommendations are based on the fact that **"the prudent choice for women who are or may become pregnant is to abstain from alcohol"**.[52]

Fetal Alcohol Syndrome (FAS) is the condition of those who suffer at the severe end of a continuum of disabilities caused by maternal use of alcohol during pregnancy. Fetal alcohol effects, FAE, is the diagnosis given the similarly caused condition when the physical symptoms are more variable and less extreme. The most recent diagnostic information originates from the 1996 United States Institute of Medicine's (IOM) delineation of multiple diagnostic categories: FAS with confirmed maternal alcohol use during pregnancy, FAS without confirmed maternal alcohol use during pregnancy, Partial Fetal Alcohol Syndrome (pFAS), Alcohol Related Neurodevelopmental Disorders (ARND), and Alcohol Related Birth Defects (ARBD).[53] FAE (largely replaced by the pFAS and ARND of the IOM) has been termed "the invisible disability," because affected individuals though superficially normal, may suffer central nervous system disabilities rendering them at risk for severe behavioral and cognitive problems. ARBD includes a range of congenital anomalies resulting from confirmed maternal alcohol exposure, which may involve heart, skeletal, vision, hearing, and fine/gross motor problems. FAS and FAE remain the terms referred to in the bulk of the literature on diagnostic criteria and prevalence studies. Collectively, these two most commonly-used diagnostic categories are denoted FAS/E. Furthermore, the total spectrum of disorders lies under the umbrella term, Fetal Alcohol Spectrum Disorders (FASD).[54] The incidence of FASD is estimated at 9.1 per 1000 live births in the population.[55]

Co-morbidities can accompany FASD, including: attention deficit hyperactivity disorder (ADHD), Attention Deficit Disorder (ADD), oppositional defiant disorder (ODD), attachment disorder, conduct disorder, personality disorder, and depression and suicide. FASD conditions may be misdiagnosed as one of these co-morbidities, especially ADHD among the middle class.[56]

FASDs are the leading cause of mental retardation, surpassing Down's syndrome and spina bifida. As brain damage occurs when the child is exposed to alcohol *in utero*, effects are not merely a matter of developmental delay. Rather, they are permanent and irreversible.[57]

2.2 Cause of FASDs

As the cause of FAS/E is maternal alcohol use during pregnancy, it is *prima facie* a completely preventable condition. However, when underlying causes of alcohol abuse, such as poverty and marginalization are considered, a solution is not obvious. It is not simply a matter of education about dangers of drinking during pregnancy. Interventions tried with pregnant mothers will be discussed under the heading, Secondary Prevention, Section 5.1.5.

The earlier in the term of pregnancy alcohol is introduced, the more severe damage to the fetus likely will be. Degree of damage depends on many factors including *inter alia*: nutrition, genetics of the mother and the fetus, amount of alcohol consumed, the mother's metabolic rate, blood alcohol content (BAC), pattern of consumption, timing of consumption, and general health. As previously noted, the fetus is more susceptible to damage from

[52] Health Canada and Canadian Pediatric Association, Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) in Canada, 1996, http://www.hc-sc.gc/english/media/releases/1996/96-72e.htm.

[53] Stratton, K.R., How, C.J. Battagalia, F.C., Institute of Medicine. *Fetal Alcohol Syndrome—Diagnosis, Epidemiology, Prevention, and Treatment*. (Washington, D.C.: National Academy Press, 1996).

[54] Streissguth, A., and O'Malley, K. "Neuropsychiatric Impliations and Long-term Consequenes of Fetal Alcohol Spectrum Disorders." Vol. 5, No. 3 (2000) Seminars in Clinical Neuropsychiatry, p. 177-190; and Third Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable (September 9, 2002), *FAS: When the Children Grow Up*, retrieved September 30, 2002, from the World Wide Web: http://www.knowtv.com.

[55] Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P, Hanson JW, Graham JM (1997) "Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder." *Teratology* 56: 317–326.

[56] Philp, M. "Middle-class FAS: A Silent Epidemic?" Saturday, February 1, 2003, Globe and Mail, page F6.

[57] *Supra* note 18 at 9. (Streissguth, A Guide for Families).

alcohol than is the mother, as the fetal system does not metabolize alcohol as does the mother's system; thus alcohol accumulates to a higher concentration in the fetus.[58]

Mechanisms for alcohol teratogenicity are thought to involve ready absorption of low molecular weight alcohol across the placenta. Once it crosses the placenta it can affect developing fetal cell structures through induced chromosomal abnormalities and enzymatic malfunction, leading to malformation, dysmorphology and growth deficiencies. This mechanism is coupled with a tendency of alcohol metabolism to induce oxidative stress. Cell metabolism is altered by the presence of alcohol, which functions as a vasoconstrictor particularly at the umbilical cord site. The combined effect is fetal hypoxia or oxygen deprivation, with subsequent organic brain damage. Oxidative stress is the key mechanism of brain injury throughout the entire FASD spectrum.[59]

2.3 Incidence

Incidence and prevalence data are somewhat problematic, in part due to the manner in which disease statistics are coded and collected. No codes existed under the World Health Organization International Classification of Diseases, ICD-9 system, for statistical reporting of fetal alcohol syndrome itself. The disease monitoring code 760.71, "noxious influences affecting fetus via placenta or breast milk, specifically alcohol; includes fetal alcohol syndrome" was used for collection of data for health statistics.[60] However, other conditions, such as exposure to mercury or other noxious substances, may have been included in 760.71. ICD-9 system has been replaced by ICD-10 codes, which has Q86, a more FAS-specific code, "congenital malformation syndromes due to known exogenous causes, not elsewhere classified."[61] According to a medical expert, Q86 eliminates problems of other teratogens, but does not allow for separate coding of pFAS, ARND, or ARBD. Q86 could be a general code for FASD, but appears to be used primarily for FAS.[62] In British Columbia an agreement with Vital Statistics allows for the use of Q86 with an addendum to accommodate for the addition of the 4-digit Seattle code;[63] the Seattle code would allow for a refinement of the ICD-10 code, Q86, to include the other prenatal alcohol diagnoses.[64] Unlike other Canadian jurisdictions where FASDs are not reportable conditions, in the sense that physicians billings report only those conditions presenting for treatment (such as a cold or flu), theYukon, under the authority of the *Public Health & Safety Act*, R.S.Y., c-176., does require mandatory reporting of FAS:

> 2(b) the reporting by every medical practitioner of persons under their treatment suffering from Fetal Alcohol Syndrome;

Since mandatory reporting was introduced in 2000, eleven names have been put forward by Yukon physicians and those came from only two doctors, rendering such mandatory reporting not an accurate reflection of prevalence and incidence of FASD in the Yukon. Physicians were required to forward information on diagnosis to a confidential registry; however, physicians proved reluctant either to forward information or to diagnose.[65]

[58] Third Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable (September 9, 2002), *FAS: When the Children Grow Up*, retrieved September 30, 2002, from the World Wide Web: http://www.knowtv.com.

[59] Cohen-Kerem, R. and Koren, G. *Antioxidants and Fetal Protection Against Ethanol Teratogenicity,Review of Experimental Data*. (Third Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable, Sept. 9 2002, *FAS, When the Children Grow Up*, retrieved September 30, 2002, from the World Wide Web: http://www.knowtv.com).

[60] *Supra* note 52. *International Classification of Diseases*, ninth edition (ICD-9-CM), cited in: Stratton K., Howe, C., % Battaglia F. (Eds).(1996). *Fetal Alcohol Syndrome, Diagnosis, Epidemiology, Prevention and Treatment*. Washington, D.C.: National Academy Press, at. 83.

[61] *The International Statistical Classification of Diseases and Related Health Problems* (ICD). The tenth Revision (ICD-10) was published in 1992, but not scheduled for implementation n Canada until 1998-1999 and in the United States, 1999-2000. Since 1948, the World Health Organization (WHO) has been responsible for ICD, publishing four revisions: ICD-6, 1948; ICD-7, 1955; ICD-8, 1965; ICD-9, 1975; and ICD-10 in 1992. ICD has become the international standard classification for all general epidemiological and many health management processes. Retrieved January 19, 2004, from the World Wide Web: http://www.who.int/whosis/icd10/.

[62] Blakley, P., M.D.., Kinsmen Children's Centre, Alvin Buckwold Clinic, Saskatoon, SK, e-mail communication of January 18. 2004.,

[63] Astley, S. J. & Clarren, S.K., "Diagnosing the Full Spectrum of Fetal Alcohol-Exposed Individuals—Introducing the 4-digit code," (2000) 35(4) Alcohol and Alcoholism, 400-410, Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network (DPN), http://alcalc.oupjournals.org/cgti/content/full/35/4/400. The four digits represent the magnitude of exposure of the four key diagnostic features of FAS: (1) growth deficiency; (2) facial phenotype; (3) central nervous system damage/dysfunction; and (4) gestational alcohol exposure. A coding of "1" reflects complete absence of the FAS feature, and a coding of "4" reflects a strong classic presence of the FAS feature. Codes can range from 1111-4444. Ranges of values can be selected for the other prenatal alcohol diagnoses.

[64] *Supra* note 62. (Dr. Blakley)

[65] FAS Registry Numbers. Patricia.Living@gov.yk.ca. E-mail communication of February 3, 2004.

In addition, neither the diagnostic criteria for FASD, nor their application, have been consistent. National guidelines pending from Health Canada will in future assist standardization of diagnoses. Studies on FASD specifically have been limited to certain clinical or hospital populations, or to certain isolated communities where alcohol consumption is known to be high. Not being representative samples, they are not generalizable to the population as a whole.

Mindful of these limitations, the present estimate of the world incidence of FAS is 1.9 cases per l000 live births.[66] Currently, no national data for Canada exist, although Health Canada estimates the incidence at 1 to 3 per 1000.[67] It appears that the incidence of FAS/E is much higher among certain Aboriginal groups,[68] standing at 192 in 1000 live births in a British Columbia community where alcohol consumption was high.[69] A study of a Manitoba community reported a rate of l00 individuals affected by prenatal consumption of alcohol per 1000 live births.[70] Based on a selected group, an informal study placed the proportion of young persons incarcerated at 23.3 % FAS/E.[71] A study of young offenders appearing in provincial court indicated that nearly 50% had prenatal exposure to alcohol.[72] Projected prevalence rates in the general population applied to total prison populations predict a much smaller proportion (approximately 1%). This likely indicates that carceral populations are not representative samples of the general population. Moreover, only one-third of the 1% cases expected have been identified in the prison system. This is not surprising as none of the federal or provincial prisons or correctional centres studied reported having a screening program for FAS.[73] Access to diagnostic services is problematic, rendering prevalence statistics in most populations underestimations.[74] A paper published by Correctional Services Canada recommends:

> [That] [t]he criminal justice system begin its own pre-sentence investigative screening to determine if the individual in question has ever received a diagnosis of FAS/FAE.[75]

Waiting lists at diagnostic clinics across Canada range from 6 months to one year for children. National standards are being developed for diagnosis, with a view to their potential inclusion in the DSM-IV.[76] Many methodological problems exist, notwithstanding the diagnostic issues, in measuring incidence and prevalence rates. Estimates for Aboriginal incidence, in particular, must be assessed according to the context of isolated reserve communities and specific clinical population samples in which they were made, restricting the scope of generalization of these estimates. Moreover, considering FAS/E is a global issue, not solely an Aboriginal problem, Aboriginal incidence statistics are comparable to other marginalized populations where similar conditions abound: South Africa, Rumania, Russia, China and South America.[77]

[66] *Supra* note 10. Tait, C. "Fetal Alcohol Syndrome Among Canadian Aboriginal Peoples: Review and Analysis of the Intergenerational Links to Residential Schools," (Aboriginal Healing Foundation, 2002) at 91-117.

[67] Health Canada, http://www.hc-sc.gc/english/media/releses;1996/96-72e.htm. Health Canada and Canadian Pediatric Association, Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) in Canada, 1996, http://www.hc-sc.gc/english/media/releases/1996/96-72e.htm

[68] Standing Committee on Health and Welfare, Social Affairs, Seniors and Status of Women, 34th Parliament, 3rd Session, No. 10-22, index 1992-1993, 1-29 at 4, "Foetal Alcohol Syndrome, A Preventable Tragedy," (Ottawa: Queen's Printer for Canada, 1988-1992).

[69] Robinson, G.C., Conry, J.LO. and Conry, R.F. "Clinical Profile and Prevalence of Fetal Alcohol Syndrome in an Isolated Community in British Columbia," (1987) 137 Canadian Medical Association Journal, 203-207.

[70] Square, D. (1997). Fetal Alcohol Syndrome Epidemic in Manitoba Reserves. Canadian Medica*l Associat*ion Journal. 157:59-60.

[71] Fast, D.K., Conry, J.L., and Loock, C.A., "Identifying fetal alcohol syndrome (FAS) among youth in the Criminal Justice System, (1999) 20 (5) Journal of Developmental and Behavioral Pediatrics, 370-372;

[72] Zakreski, D. (March 10, 1998) Fetal Alcohol Syndrome Linked to Crime. Saskatoon Star Phoenix.

[73] Burd, L., Selfridge, R., Klug, M.G. and Juelson, T. Fetal Alcohol Syndrome in the Canadian Corrections System, September, 2003 J FAS Int., **e14,** The Hospital for Sick Children.

[74] *R.* v. *Gray,* 2002 B.C.J. No. 428 (B.C.S.C.). Boland, F. J., Burrill, R., Duwyn, M. and Karp, J., *Fetal Alcohol Syndrome: Implications for Correctional Services*, (Correctional Services Canada, 1998), which recommends that the criminal justice system begin its own pre-sentence screening for FASDs.

[75] Boland, F.J., Burrill, R., Duwyn, M. & Karp, J. (1998). *Fetal Alcohol Syndrome: Implications for Correctional Services.* Ottawa: Correctional Services Canada.

[76] Cook, J. L. *FAS Diagnosis, Health Canada's Activities,* (Third Annual Fetal Alcohol Canadian Expertise (FACE) Roundtable, Sept. 9, 2002, *FAS, When the Children Grow Up.* Retrieved September 30, 2002, from the World Wide Web: http://www.knowtv.com); Cook, J. and Huffine, C. "It's Time Psychiatry's Diagnostic "Bible" Addresses FAS," Iceberg: An Educational Newsletter for People Concerned about Fetal Alcohol Syndrome (FAS) and fetal alcohol effects (FAE), vol. 10, issue 2, 2000, p. 1-2. Note: The DSM-IV is the *Diagnostic and Statistical Manual of Mental Disorders* (Washington, DC: American Psychiatric Association, 1994).

[77] *Supra* note 10 at 113-117. (Tait) and (Gibson, F., *Home is my Road* and the CBC radio program discussion with the author on "Between the Covers," April 15, 2003, 10:00 p.m.).

Despite the lack of scientifically rigorous data, there is no denying that FASDs in Canada are prevalent among native populations:

> FAS is not a problem unique to Canada's native peoples but it is particularly prevalent among them. The National Native Association of Treatment Disorders estimates that 80 per cent of aboriginal people in Canada are affected by alcoholism, either through being addicted themselves or through dealing with the addiction of a close family member (Fournier and Crey 1997: 174). A leading researcher in the field, Albert Chudley, asserts that every native child adopted in the last two decades has suffered alcohol damage in utero, and that this fact—rather than alienation from white society—is at the root of their difficulties later in life (*ibid*.). Chudley may or may not be overstating his case, but there can be no doubt that the consequences of FAS for Canada's native population have been severe. Records from medical institutions in Saskatchewan showed that in the past decade, out of 450 children born with FAS/FAE 75% were aboriginal (Fournier and Crey 1997: 178). (116).[78]

Locally, regarding the non-offender population, in the 2003 calendar year, doctors referred 186 children to the Alvin Buckwold Child Development Program at the Kinsmen Children's Centre in Saskatoon, SK, for Fetal Alcohol Syndrome diagnostic assessments. With follow-up reviews, a total of 221 clients were seen through the Fetal Alcohol Syndrome Clinic. The mean age of clients at first evaluation is about six years. Costs of Fetal Alcohol Syndrome Assessments for non-offenders range from $350 to $1359, depending on the professionals involved in the assessment.[79] Included in estimated costs are: direct patient contact, preparation time, report writing, and liaison with schools, Department of Community Resources and Employment, and other agencies. Professional membership of the diagnostic team varies with the age of the client as follows:

- children under two are evaluated by a physician (MD, physical therapist (PT), occupational therapist (OT), and speech-language pathologist (SLP);
- children two to six are evaluated by an MD, psychologist, and PT/OT/SLP as indicated by client history;
- children seven and older are evaluated by an MD; and
- all new and some review appointments include appointments with a social worker (SW).

Based on client referrals, The Alvin Buckwold Child Development Program estimates a prevalence figure in Saskatchewan of 0.59 per 1000 population. This may be considered a gross underestimation as the clinic sees only children referred by a physician.[80]

The Regina Hospitals, the General and the Pasqua, together report 16 out of 2993 births in the period April, 2001 to March, 2002, and 9 out of 2882 births in the period April 2002 to March, 2003, yielding FAS incidence rates of 5.3 and 3.0 per 1000, respectively. During the time periods at issue, 8 and 17 clients, in addition to newborns, were seen respectively in the two years at the two facilities.[81]

The Royal University Hospital, Saskatoon City Hospital, and St. Paul's Hospital, in Saskatoon, report a total of 4 births out of 3,997 in 2001-02, and 2 births out of 3,832 in 2002-03, yielding FAS incidence rates of 1 and 0.5 per 1000 respectively. During the same time periods, 21 and 34 clients, in addition to newborns, were seen respectively in the two years at the three facilities.[82] Documentation and coding practices affect these statistics. In addition, newborns may not be diagnosed at the time of birth unless the physical indicia and evidence of maternal consumption are apparent. Prior to age two, some children with FAS do not show all the facial

[78]Adams, M. *Our Son a Stranger, Adoption Breakdown and its Effects on Parents,* Montreal: McGill-Queen's University Press, 2002, at 136.

[79]Dr. Blakley, Alvin Buckwold Child Development Program, Kinsmen Children's Centre, telephone communication, January 8, 2004.

[80]*Supra* note 79. (Dr. Blakley)

[81]Heath Information Analyst, Regina Qu'Appelle Heath Region, e-mail communication of January 22, 2004, with LeeAnn Carr, LeeAnn.Carr@rqhealth.ca.

[82]Health Information Management Services, Sharon McMillan, Analyst, Royal University Hospital, Saskatoon, Saskatoon District Health, facsimile of February 4, 2004.

features or do not have evidence of CNS dysfunction of prenatal origin.[83] Unless FAS is the primary reason for treatment or admission, the condition, even if documented, may not be coded, as it is not mandatory to code secondary diagnoses.[84]

Province-wide, according to Court Services, FAS/FAE court-ordered assessments for April 1, 2002 - June 30, 2003 totaled 78. These assessments yielded the following diagnostic results: 2 FAS; 42 pFAS; 18 ARND; 2 prenatal alcohol category; and 14 with no confirmed prenatal alcohol exposure. Most of this sample of 78 were young offenders. The total cost of these assessments was $78,725.66.[85] The mean cost is $1009.30 per assessment, while the estimated mode or most frequent billing cost is $1650.00, with neuropsychological assessments being one of the higher costs. Physician FAS assessments were relatively low cost, at $557.50. Costs vary with the nature of the assessment, whether forensic-psychiatric, neuropsychological, family, FAS, or psychological. Various judges ordered assessments, and a variety of service providers carried them out. Judge Whelan ordered 30 assessments;[86] Dr. Jo Nanson carried out 30,[87] while Dr. Blakley did 26,[88] due to their expertise in FASD. It appears that clinical assessments are more economical than court-ordered assessments, while contributing to early diagnosis and treatment of FASD with resultant avoidance of the criminal justice system. Contact with the criminal justice system cannot occur before the age of 12, when it is too late for significant early intervention.

2.4 Characteristics of FASDs

2.4.1 Primary Characteristics

Primary characteristics of fetal alcohol syndrome include:

- General growth deficiencies (reductions in body weight, height and head circumference);
- Structural abnormalities which are primarily facial: short palpebral folds (small eye openings), epicanthic folds (extra skin folds close to nose), long and flattened philtrum (groove under nose), flattened maxilla (jaw and midface), shortened nose; and
- Central nervous system abnormalities associated with impairment of both cognitive abilities and behavioral or adaptive functioning (neurological abnormalities, behavioral dysfunctions, developmental delays and intellectual impairment).[89]

For individuals with FAE, the presence of the first two primary characteristics is more subtle, or may be absent; however, the last, most serious characteristic is pervasive throughout the FASD due to the devastating effect of alcohol on the developing nervous system.[90]

[83] *Supra* note 53 at 73. (Stratton, Howe & Battaglia, IOM)

[84] *Supra* note 82. (Health Information Management Services, Sharon McMillan, Analyst, Royal University Hospital, Saskatoon, Saskatoon District Health, facsimile of February 4, 2004.)

[85] Court Services, e-mail communications, January 12, 2004: from Christa Klatt, cklatt@justice.gov.sk.ca and Linda Bogard, lbogard@justice.gov.sk.ca.

[86] Judge Whelan's benchmark decisions in *R*. v. *J.A.P*. [2000] S.J. No. 260, *R*. v. *WALD*(1) {2002] S.J. No. 221, and *R*. v. *WALD*(2) [2002] SKPC 37, establish the framework for UST analysis (the last two cases involved young persons with FAS). In *R*. v. *R.F*. [2002] S.J. No. 742, R.F. was pFAS, and found not Criminally Responsible (NCR), but her disability served as a mitigating factor in sentencing.. *R*. v. *S.L.P*., [2002] S.J. No. 311, concerned another youth with pFas, neither UST or NCR, but whose disability served as a mitigating factor in sentencing. In the context of a Crown request for presentence detention, the presumption against detention in s. 29(2) of the *YCJA* was analysed in *R*. v. *C*.(W.S.), [2003] SKPC 183 and found applicable in her case, an issue which as implications for FASDs and the community-based treatment they require. A presentence report was ordered and C. (W.S.) was referred for assessment . Judge Whelan takes a particular interest in young persons in her court, and disabilities such as FASD. She is one of the judges mentioned (along with Judge Turpel-Lafond) in Deanna Driver's "Saskatchewan Judges Lead Fight for Handling of FASD Victims," 23(11), *The Lawyers Weekly*, July 11, 2003.

[87] Dr. Jo Nanson is one of the few neuropsychologists in the province, has done many FASD assessments and also publishes and presents on the topic of FASD.

[88] Dr. P. Blakley is Medical Director of the Alvin Buckwold Childhood Development Program, and is Director of the Provincial Clinical Teratology Program, Department of Pediatrics, Royal University Hospital. She performs many of the physician FASD assessments for the clinic and for the courts.

[89] Jones, K.L., & Smith, D. W., "Recognition of Fetal Alcohol Syndrome in Early Infancy" (1973) 2(836) Lancet 999-1001; and Smith, D. W. *Recognizable Patterns of Human Malformation: Genetic,Embryologic and Clinical Aspects* (3rd ed.) (Philadelphia: W.B. Saunders, 1982).

[90] Clarren, S.K. & Smith, D. W., "The Fetal Alcohol Syndrome" (1978) 298(19) New England Journal of Medicine, 1063-1067; Hanson, J.W., Streissguth, A. P., & Smith, D. W., "The Effects of Moderate Alcohol Consumption during Pregnancy on Fetal Growth and Morphogenesis" (1978) 92(3) Journal of Pediatrics, 457-460; and Smith, D. W ,"Fetal Alcohol Syndrome and Fetal Alcohol Effects" (1981) 3 Neurobehavioral Toxicology and Teratology, 127.

2.4.2. Secondary Characteristics

Without appropriate intervention, FAS/FAE individuals risk developing secondary, antenatal disabilities, because of their cognitive and adaptive impairments. These disabilities, not present at birth, likely can be attenuated as victims mature through ongoing, effective interventions. Streissguth and others identified the following secondary disabilities in their 1996 study that considered a cohort of over 400 FAS/FAE individuals, ranging in age from six to fifty-one years:

- over 90% of those 6 and over experienced mental health problems;
- 60% of those 12 and older were either expelled, or suspended, or voluntarily dropped out of school;
- 60% of those 12 and over were charged with and/or convicted of a crime;
- approximately 50% of those 12 and over were institutionalized or utilizing in-patient treatment programs;
- 50% of those 12 and over had been involved in inappropriate sexual behavior; and
- 35% of those 12 and over experienced problems with alcohol and drugs.[91]

In the same 1996 study, Streissguth identified in her sample the following protective factors that attenuated the development of secondary characteristics in her sample:

- Living in a stable, nurturing home;
- Receiving developmental disability services early;
- Being diagnosed before six years of age.
- Not having frequent moves; and
- Not being a victim of violence;[92]

Surprisingly, Streissguth found higher rates of secondary disabilities in individuals who had FAE rather than FAS and who had an IQ higher than 70. She speculated that FAE individuals, lacking obvious bio-markers, are not diagnosed as early, and do not receive developmental disability services to the same extent as FAS individuals. This may account for the higher rates of secondary disabilities developing in this FAE population, and underlines the importance of protective factors in ameliorating secondary characteristics.[93]

Hallmarks of ARND, and other conditions included under the FASD label include: attentional and memory deficits, impulsivity, inability to appreciate consequences of actions, and lack of executive functioning. Executive functioning includes the capacity to think in a flexible way, to use feedback to modify behavior, and to use higher level conceptual thinking. FASDs who lack executive functioning often persist with an unsuccessful strategy over a considerable period of time, even when facing frustration.[94]

Streissguth and O'Malley[95] recommend supports over the lifespan of affected individuals, including the following adult interventions: sheltered living, job training, ongoing employment supervision, assistance with money and life management, and positive role models. Interventions recommended for each stage of the life cycle are included in the statements of best practices articulated by Health Canada.[96]

[91]Streissguth, A. P., Barr, H.M., Kogan, J., & Bookstein, F.L. *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE): Final Report to the Centres for Disease Control and Prevention on Grant No. R04/CCR008515* (Tech. Report No. 96-06) (Seattle: University of Washington, Fetal Alcohol and Drug Unit, 1996), cited in A. P. Streissguth, *Fetal Alcohol Syndrome: A Guide For Families* (Toronto: Paul H. Brookes Publishing Co., 2001) at 107-112.

[92]*Supra* note 18 at 110-111. (Streissguth, a Guide for Families)

[93]*Ibid*. at 111-112. (Streissguth, A Guide for Families)

[94]*Supra* note 5. *R. v. M.B.*, [2003] S. J. No. 377 (Sask. Provincial Court). Expert Opinion of Dr. Jo Nanson.

[95]Streissguth, A. P. and O'Malley, K., "Neuropsychiatric Implications and Long-term Consequences of Fetal Alcohol Spectrum Disorders" (2000) Vol. 5. no. 3 Seminars in Clinical Neuropsychiatry. 177-190.

[96]Roberts, G. and Nanson, J. Health Canada, *Best Practices, Fetal Alcohol Syndrome/ Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy* (Health Canada, Canada's Drug Strategy Division, 2000). Refer to "Best Practices Statements" 7.1.5 (infancy and early childhood), 7.2.5 (later childhood), 7.3.5. (adolescent interventions), and 7.4.5 (adult interventions).

3 PREVENTION

3.1 Primary Prevention

Considering an estimated 50% of women in childbearing years consume alcohol and an estimated 50% of pregnancies are unplanned, a significant number of fetuses may be exposed to the risk of alcohol teratogenicity.[97] To deal with this risk, primary prevention focuses on the prevention of drinking, or, as an alternative, on the prevention of pregnancy. Product labeling, education, and assuring access to birth control are strategies employed.

Hankin reports a decrease in antenatal drinking associated with warning labels on alcoholic beverages, albeit a decrease small in size that does not impact the heaviest drinkers.[98] Product labeling (warning of birth defects and possible FAS) for alcoholic beverages was introduced in the U.S. in 1989 by passage of the *Alcohol Beverage Labeling Act*.[99] Subsequently, product warning labeling was considered in Canada with the introduction of private members' Bill C-222, *An Act to Amend the Food and Drug Act*, April 25, 1996. Bill C-222 unfortunately was never enacted. Warning labels, therefore, not required in Canada for alcohol products, paradoxically, must be placed on Canadian alcoholic beverage containers exported to the U.S.[100]

Warning labels serve to reinforce, but not to replace, other strategies. They should be used, not in isolation, but as part of a comprehensive strategy including initiatives in: education (pamphlets, books, media advertisements, videos, speakers, curricula), public policy, and treatment services. In Saskatchewan, warning labels are stamped on the brown carry-out bags for products purchased at liquor stores, but not on the products themselves. Brown carry-out bags, however, can be out of stock, and, when in use, often are removed, unread by the consumer. The Yukon and Northwest Territories introduced product warning labels for alcohol in 1991-2.[101] The Yukon warning label reads:

WARNING
DRINKING ALCOHOL DURING
PREGNANCY CAN CAUSE
BIRTH DEFECTS[102]

In addition, social responsibility messages are printed on the brown carry-out bags in the Yukon, including, *inter alia*, "Drinking while pregnant can harm your baby." Regardless of their limitations, product warning labels are the last line of defense before *in utero* damage can occur.

In lieu of product warning labels, the Saskatchewan Liquor and Gaming Authority (SLGA) provides support for such social responsibility initiatives as: anti-drinking and driving campaigns, programs aimed at educating the public on the dangers of drinking during pregnancy, the designated driver program, identification programs ("Please Bring your ID"), as well as national awareness campaigns in conjunction with the Canadian Association

[97] *Supra* note 59. Cohen-Kerem, R. and Koren, G. *FAS, When the Children Grow Up: Antioxidants and Fetal Protection Against Ethanol Teratogenicity*, Third Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable, 2002, retrieved September 30, 2002 from the World Wide Web: http://www.knowtv.com.

[98] Hankin, J.R., "Fetal Alcohol Syndrome Prevention Research," (2002) 26(1) The Journal of the National Institute of Alcohol Abuse and Alcoholism 58-65.

[99] *PL* 100-690; passed in 1988, came into effect in 1989. The *Act* mandates a warning on the label of each alcoholic beverage container sold in the United States: 1) *According to the Surgeon General, women should not drink alcoholic beverages because of the risk of birth defects* 2) *consumption of alcoholic beverages impairs your ability to drive a car or operate machinery and may cause health problems.* By 1981 the Surgeon General of the United States had advised women to avoid all alcohol during pregnancy. In 1970, Congress passed a law creating the National Institute on Alcohol Abuse and Alcoholism (NIAAA) to support research on alcohol abuse and alcoholism, including research on alcohol and pregnancy, including FAS.

[100] *Fetal Alcohol Syndrome and Alcohol Policy, Policy Framework, Warning Labels Bills/Motion,* Apolnet (Alcohol Policy Network), retrieved February 14, 2003, from the World Wide Web: http://www.apolnet.org/actpacks/pf_fas.html.

[101] Parliamentary Committee, Thursday April 18, 1996: Food & Drugs (2), http://www.parl.gc.ca/committees352/sfda/evidence/02_96-04-18/sfda02_blk101.html.

[102] Yukon Liquor Corporation, Social Responsibility, retrieved January 29, 2004, from the World Wide Web: *http://www.ylc.sk.ca.socialrespon.htm*. The actual size of the warning label is 1.25" x .88" (3.25 cam x 2.24 cm), and it is bilingual. The label is placed on every bottle sold in the Yukon.

of Liquor Jurisdictions (CALJ). In 2001-2, the CALJ sponsored a national media public awareness campaign focused on the importance of neither selling alcohol to nor purchasing alcohol for minors. SLGA is a member of the Provincial FAS Coordinating Committee, chaired by the Saskatchewan Institute on Prevention of Handicaps (SIPH), which SLGA funds to some extent. Various advertising campaigns and conferences have been sponsored, and liquor store product bags and till tapes do display the FAS awareness message introduced in October, 1997:

HAVE ONE (ONE is CROSSED OUT AND REPLACED BY SOMEONE)

FOR THE ROAD

CHOOSE A DESIGNATED DRIVER

DRINKING ALCOHOL DURING PREGNANCY CAN HARM THE BABY

We have Fetal Alcohol Syndrome in our Community…Let's Find A Solution[103]

Although such initiatives are praiseworthy, it is important to consider the funding by liquor regulating authorities, breweries or liquor companies, of service agencies which have as part of their mandate prevention of handicaps such as FASD. Full information is not available as to how the "arm's length" nature of these arrangements is protected. While service agencies do not appear to advocate for liquor product warning labels, it must be acknowledged that they, like liquor companies, brewers, and regulators, do advocate for responsible use of alcohol. Perhaps a characteristic of corporate social responsibility among liquor companies, breweries, and their regulating authorities is to fund prevention and treatment of FASDs, in order to mitigate the damage their teratogenic products have caused over the generations and are causing currently.[104] The amount contributed, however, in no way has approached the costs of remedying the damages. Canada's brewing industry spent, according to available statistics, about $10 million in one year on "responsible use" campaigns; this expenditure must be viewed in the context of their $ 4.6 billion in annual sales and the $100 million spent on advertising to promote use of their beverages.[105] The Standing Committee on Health and Welfare estimated the entire alcoholic beverage industry in Canada in the same year spent $250 million in advertising, promotion and sponsorships, out of total of $9.6 billion in sales.[106] Increasing the amount contributed while maintaining "arm's length" arrangements between the alcohol beverage industry and funded service agencies is paramount, so that advocacy, ethics, and programming of needy service groups are not compromised in any way. Perhaps blind trusts could be established to promote substantial, fuller mitigation, ensuring no "strings" would be attached. *The Olivieri Report*[107] contains recommendations for protecting research ethics in the context of corporate sponsorship, which may be of relevance, particularly those regarding conflict of interest and protection of academic freedom. Protection accorded academic freedom may be extended to similar forms of freedom of expression in other contexts.

Mandatory product labeling of all alcohol products is a practical strategy that might address prevention. The liquor cartel[108] is very powerful, however, and has been so in Canada since the days of the fur trade with its

[103] *Saskatchewan Liquor and Gaming Authority 2002-2003 Annual Report*, at 9.

[104] *Ibid*. It is noted that SLGA increased its FAS public awareness initiatives to $15,000 from $10,000 in previous years. No other specific mention was made of any further contribution by SLGA to FAS or SIPH in the 2002-03 Annual report; According to an e-mail received from Motherisk on September 15, 2003, susan.santiago@sickkids.ca, Motherisk receives $150,000 annually from Canada Brewers' Association (CBA) to help fund its toll-free Substance Use Helpline (1-877-FAS INFO) and to sponsor Fetal Alcohol Canada Expertise (FACE). According to the Motherisk website, retrieved Oct. 16, 2003 from the World Wide Web, http://www.motherrisk.org, CBA also funds the FAS Resource Centre at the Canadian Centre for Substance Abuse. At the Motherisk web-site, CBA reports having spent over $100 million in promotion of responsible drinking over a ten year period.

[105] *Supra* note 68. Standing Committee on Health & Welfare, Social Affairs, Seniors & the Status of Women, "Foetal Alcohol Syndrome," 3rd Session, 34th Parliament, No.s. 10-22, 1992-1993 Index, 1-29.at 14-15.

[106] *Ibid*. at 1 and 15. (Standing Committee on Health & Welfare).

[107] *Report of the (CAUT) Committee of Inquiry in the Case Involving Dr. Nancy Olivieri, the Hospital for Sick Children and the University of Toronto, and Apotex Inc.* Recommendations 1, 10, 11, 12, 15, 16, 19, 20, 21, 22, 23, 24, 25, 27, 30, and 31. Retrieved on September 20, 2003, from the World Wide Web: http://www.caut.ca/english/issues/acadfreedom/Olivieri%20Inquiry%20Report.pdf. January 22, 2004, the Federal government announced the formation of a National Ethics Research Review Board for research dealing with human subjects.

[108] Barber, K. (Ed.) *The Canadian Oxford Dictionary*, 2001: "Cartel" is used, not in the older sense of price fixing among a group of manufacturers, but in the newer sense of "political combination between parties." Such combination is intended here to include the manufacturers, distributors, retailers, and government regulators.

concomitant "whiskey trade," continuing into the period of lucrative rum running across the American border during the U.S. prohibition era, 1921-33, to current resistance to the use of warning labels. This cartel has evaded product labeling, partly through sponsoring research and harm prevention initiatives in partnership with needy service agencies. However, as noted, money donated by the cartel to captive worthy causes neither approaches the value of the profits it gleans, nor begins to address damage caused by the intoxicating, addictive, teratogenic substance it purveys.[109]

Education is another important strategy of prevention. The Frontier School Division in Manitoba has implemented a curricular initiative in the way of fetal alcohol prevention, "Making the Right Choices," for grades 5-8:[110]

- The Grade 5 curriculum deals with awareness of alcohol and tobacco use and accompanying risks during pregnancy. Learning techniques recommended include: opinion polls, information sheets about FASDs, reading and discussing a short story entitled *Jocelyn's Island* (the story of a young Aboriginal girl who becomes concerned about her pregnant sister who is going to parties), learning definitions of FAS and ARND and related vocabulary, the writing of imaginary letters to a pregnant friend explaining to her why she should stop drinking, and the making of posters about the risks of drinking during pregnancy to be displayed in the community.
- The Grade 6 curriculum expands upon the diagnostic terms FAS and ARND and other terminology, explores the reasons why some people drink, involves the students in research about FAS and ARND, and presents a short story entitled *Jeremy and Joey*, about step-brothers, one of whom has FAS, and how brother, family and school learn to respond effectively to his needs.
- The Grade 7 curriculum reviews FASD, and examines the role of media advertisements and messages regarding alcohol and drug use. Appropriate responses to these media messages are drafted by the students.[111]
- The Grade 8 curriculum introduces the mechanism of how alcohol is transferred to the fetus and its mode of attack on the fetus at various stages of development. The role of males in FASD causation is discussed. The culminating student activity is the preparation of brochures about fetal alcohol syndrome.

A sensitive approach to curriculum is recommended, to avoid stigmatizating or frightening those involved, including adopting respectful language, tone and substance. Parents are to be informed in writing that the prevention curriculum will be taught. Before discussing sensitive and confidential topics, teachers are to establish clear ground rules to prevent personal comments and hurt feelings. Individual students are allowed to skip sensitive sections and support is to be provided for these students as required.

An international, national, and provincial initiative aimed at prevention has been the declaration that "Fetal Alcohol Syndrome Awareness Day," is to begin September 9 at 9:09 a.m. each year (the ninth minute, of the ninth hour, of the ninth day, of the ninth month). At this time, people are requested to show respect for the nine months each individual spends in the womb.[112]

[109] *Supra* note 68. Standing Committee on Health and Welfare, Social Affairs, Seniors and Status of Women, 34th Parliament, 3rd Session, No. 10-22 index 1992-1993, 1-29, "Foetal Alcohol Syndrome, A preventable Tragedy," (Ottawa: Queen's Printer for Canada, 1988-1992).

[110] Teaching Units on FAS, lbraun@frontiersd.mb.ca.

[111] Alcohol and Gaming Commission of Ontario, *Liquor Advertising Guidelines: Liquor Sales Licensees and Manufacturers* (Toronto: Alcohol and Gaming Commission of Ontario: August, 2003). The *Liquor Licence Act*, R. S.O. 1990, c. L-19, s. 38(1) states that no person shall advertise liquor except in accordance with the regulations enacted pursuant to this *Act*. Holders of liquor sale licences or manufacturers of liquor are responsible to ensure that the advertising carrying its business or brand name, or endorsed by it, falls within the parameters set out in the regulations and in these guidelines. Otherwise, disciplinary proceedings under the Registrar of Alcohol and Gaming may result. "Liquor" means beer, wine and/or spirits or any combination thereof. All advertising must be consistent with the principle of depicting responsibility in use or service of liquor. Responsible advertising does not imply that consumption of liquor is required to obtain or enhance social, professional or personal success; athletic prowess; sexual prowess, or any other opportunity or appeal; or enjoyment of any activity; fulfillment of any goal; or resolution of social, physical or personal problems. It should not appeal, either directly or indirectly, to persons under the legal drinking age, and should not associate or depict the consumption of liquor with driving a motorized vehicle, or with any activity that requires care and skill or has elements of danger. Advertising that is beyond the permissible scope of the *Guidelines* may result in disciplinary proceedings under the Registrar of Alcohol and Gaming and/or the issuance of an order of cessation thereunder or may result in prosecution. No doubt this *Act*, *Regulations* and *Guidelines* are models for Canadian jurisdictions. For instance the *Liquor Advertising Rules of Conduct Regulation*, Man. Reg. 125/95 under *The Liquor Control Act*, C.C.S.M. c. L160, 1995, has similar provisions to the above. In addition, *Saskatchewan Liquor and Gaming Authority Media Advertising Policy* requires prior approval from the Liquor Board of all related advertising. The criteria for approval are similar to those aforementioned.

[112] *The Fetal Alcohol Syndrome Awareness Day*, Chapter F-13.101, S.S., 2002.

3.2 Secondary Prevention

Secondary prevention focuses on harm reduction to the fetus during pregnancy. Although in secular societies, termination of pregnancy may be an option, this is not usually consonant with traditional Aboriginal cultures which view children as a special gift from the Creator. The favoured option is to offer an expectant mother access to treatment for her addictions.

Pregnant women are screened for risk when they access medical care. Risk factors related to potential alcohol consumption screened for include: poverty, poor prenatal care, poor nutrition and health, poly-drug use, prostitution or other involvement in the sex-trade, parent-partner-peer problems, psychiatric concerns, and prior abuse.[113]

Commissioned by The Prairie Women's Health Centre of Excellence, Caroline Tait authored *A Study of the Service Needs of Pregnant Addicted Women in Manitoba*,[114] which included the identification of barriers for pregnant women seeking addiction treatment. Barriers identified include:

- psychological barriers (shame, fear, alienation);
- barriers related to a woman's children (lack of childcare, fear of having children apprehended);
- barriers related to social support networks (after care services are required, otherwise a client may be isolated with an abusive, addictive partner upon termination of the treatment program);
- barriers related to socio-geographic factors (costs of travel to treatment);
- barriers related to stigma (the stigma associated with alcohol/drug use not under control, especially when involving a female); and
- barriers related to treatment programs themselves (similar programs with which the client has had previous experiences may have been philosophically and culturally inappropriate).

A forgiving, welcoming, and helpful attitude manifested by service-providers is important in eliminating another possible barrier. Disadvantaged people sometimes perceive extant health, justice, and social service agencies as judgmental, cold, and intimidating. Disadvantaged women may hesitate to access services for fear of losing welfare benefits or of having their children apprehended.[115] In some cases, women have been forcibly detained,[116] even sterilized against their will, as has transpired recently among Indigenous women of Brazil,[117] and was performed on the mentally disabled in Alberta a generation ago.[118] In present day Afghanistan, in some areas, unmarried women face being apprehended, taken to hospitals, and coerced into enduring gynecological examinations to determine their chastity.[119] Poverty-stricken women in some parts of the world fear that their children will be abducted and sold through either adoption or prostitution.[120] Knowledge of situations such as these may render marginalized women wary of accessing services.

[113] *Supra* note 56. Philp, M."Middle-class FAS: A Silent Epidemic?" Globe and Mail, February 1, 2003. Middle class women may avoid detection for these risk factors. However, they do have the economic wherewithal to consume considerable amounts of alcohol. Their affected offspring are more likely to be diagnosed as ADHD, rather than with one of the FASDs, and they are better able to afford private schools or tutoring and the kinds of supports and advocacy that affected children require. Retrieved February 3, 2003 from the World Wide Web: http://www.globeandmail.com.

[114] Prairie Women's Health Centre of Excellence, retrieved February 3, 2003 from the World Wide Web: http://www.pwhce.ca/epaw.htm.

[115] *Supra* note 14. Ridd, D. *Pregnant Addicted Women: Manitoba's Experiences.* (Third Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable (September 9, 2002), *FAS: When the Children Grow Up*, Retrieved September 30, 2002, from the World Wide Web: http://www.knowtv.com.)

[116] *Winnipeg Child and Family Services (Northwest Area* v. *D.F.G.* (1997), 152 D.L.R. (4th) 193 (S.C.C.). An expectant, addicted mother was forcibly detained in a hospital to protect her unborn child. The Supreme Court held that such detention violated her *Charter* rights.

[117] Johnson, B. F.,,"Stolen Wombs: Indigenous Women Most at Risk." 2000 *Native Americas* 38-42; and CBC News, November 4, 2002, Forced Sterilization of the Indigenous Women of Brazil, Retrieved November 5, 2002, from the World Wide Web: http://www.CBC.ca.

[118] *The Sexual Sterilization Act, R.S.A.,* 1928, allowed for the sterilization of mentally disabled people confined to institutions within the province of Alberta (several other provinces and many states had similar laws at that time). In 1996, Leilana Muir was awarded $1,000,000 in damages for wrongful confinement and wrongful sterilization; 700 other claimants are awaiting the dispositions of similar claims (*Muir v. Alberta* [1996] A.J. No. 37).

[119] Leopold, Evelyn (December 17, 2002). "Post Taliban Warlords Oppress Afghan Women," Reuters News Agency, Human Rights Watch Report, Retrieved January 5, 2003 from the World Wide Web: http://news.findlaw.com/international/s/20021217/afghanwomendc.html.

[120] General Assembly of the United Nations, 85th Plenary Meeting, 20 December 1993, "Need to adopt efficient, international measures for the prevention of sale of children, child prostitution and child pornography," A/RES/48/156. Retrieved January 27, 2004, from the World Wide Web: http://www.un.or/documents/ga/rews/48/a48r156.htm.

Judgmental attitudes have been associated with maternal consumption of alcohol during pregnancy. The presumption of the personal autonomy of the expectant mother enabling her to abstain from alcohol use underlying these attitudes is questionable. In the context of an addictive, intoxicating substance, combined with such social conditions as poverty, abuse and racism, the personal autonomy of such women may be greatly diminished. Furthermore, product warning labels, virtually the last line of defense before damage to a developing fetus, are, in Canada, not utilized.[121] In addition to addressing listed barriers, implementation of Aboriginal employment equity would go far towards promoting both primary and secondary prevention through addressing underlying social conditions that perpetuate the problem.

Pharmacological intervention (antioxidant therapy) is another technique of harm reduction during pregnancy. Oxidative stress is an important mechanism in the prenatal brain injury of FAS/E fetuses. Antioxidant treatment strategies for preventing or attenuating ethanol-induced[122] oxidative stress in fetal life and its impact on brain functioning in postnatal life have been proven effective in studies involving cell cultures and animal models. In such studies, pharmacological doses of the antioxidants, vitamin C and E, were administered, along with varying doses of ethanol. Although an antioxidant protective effect against ethanol has been observed in animal studies, no data yet available indicates whether this prophylactic treatment can benefit pregnant women. Antioxidant treatment during pregnancy is not new; antioxidants such a vitamins E and C have been used in the treatment of pre-eclampsia and not found to be teratogenic. It follows that treating women who abuse alcohol during pregnancy with antioxidants such as vitamin supplements may have a protective effect against FAS/E. As well there is the benefit of addressing certain nutritional deficits that may be present, without concomitant negative effects.[123]

3.3 Tertiary Prevention

Tertiary prevention rests on early diagnosis of disorders along the FASD. Essential to the diagnosis of FAS/E is confirmation of maternal alcohol consumption during pregnancy. This may be problematic. Maternal self-report is subject to denial because of stigma and guilt. When diagnostic issues arise for the first time in later life, the birth mother may be absent. A recent breakthrough has transpired in the field of meconium studies. Meconium is the first "stool" or bowel content passed by the neonate. Chemical analysis of the meconium from the newborn's diaper can measure both gestational timing and magnitude of fetal ethanol exposure resulting from maternal drinking during the last two trimesters of pregnancy. An enzymatic reaction occurs between fatty acids in the mother's body and the ethanol she consumes, to form reliable biomarkers of fetal ethanol exposure in the meconium. Characteristic patterns of fatty acid ethyl esters (FAEEs) form, wherever maternal alcohol consumption is more than minimal, and these patterns of FAEEs can confirm and elucidate prevalence of alcohol consumption by pregnant women. Such patterns of FAEEs can provide objective, quantitative, corroborative evidence of ethanol consumption required for positive diagnosis of FAS/E, together with the presence of other criteria required to confirm the diagnosis.[124]

[121] *Supra* notes 100 and 101. (Exception: alcohol product warning labels are used in the Yukon and the Northwest Territories. Thursday April 18, 1996- Parliamentary Committee: Food & Drugs (2), http://www.parl.gc.ca/committees352/sfda/evidence/02_96-04-18/sfda02_blk101.html; and Yukon Liquor Corporation, Social Responsibility, http://www.ylc.yk.ca/socialresp.htm.)

[122] Ethanol is the chemical name for the alcoholic component of intoxicating beverages.

[123] *Supra* note 59. Cohen-Kerem, R. and Koren, G. and *Antioxidants and Fetal Protection Against Ethanol Teratogenicity*, (Third Annual Fetal Alcohol Canadian Expertise (FACE) Roundtable, September 9, 2002, *FAS, When the Children Grow Up*, retrieved September 30, 2002, from the World Wide Web: http://www.knowtv.com.)

[124] Chan, D. *Neonatal Screening for Prenatal Alcohol Exposure* (Third Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable, September 9, 2002, *FAS, When the Children Grow Up*, retrieved September 30, 2002, from the World Wide Web: http://www.knowtv.com).

3.4 Prevention of secondary disabilities

Various programs have been designed and implemented to address prevention of the development of secondary disabilities post-natally. The pioneer researcher in this field is A. P. Streissguth, Seattle, Washington. Streissguth developed the Parent-Child Assistance Program (P-CAP), and its precursor, the Birth to Age Three Program[125] Such programs typically involve an intensive, paraprofessional mentorship over a minimum three-year period, for high risk mothers with addiction problems and/or previously affected births. Paraprofessional mentors mobilize support for healthy lifestyles through post-treatment care, and help to attenuate the development of secondary symptoms in the children. For example, Norway House Cree Nation, a northern Manitoba reserve community, has developed a program along lines similar to Streissguth's to provide culturally appropriate supports to parents and children. This program is termed Steps and Stages for Mom and Baby. In conjunction with a school division, it utilizes the Parents as Early Educators or PEER program that bridges the transition into the school years. Manitoba health has implemented a similar program, STOP FAS, at four sites: Winnipeg (2 sites), The Pas, and Thompson.

Toronto's Breaking the Cycle (BTC), delivers similar mentoring programs, as well as promoting partnering among prenatal, perinatal, and postnatal service networks, entailing: housing, physical and mental abuse reduction, healthy babies programs, nutrition, and substance abuse recovery. BTC utilizes a single access model to provide various services: childcare, mentoring, basic needs support (daily breakfast and lunch, transportation, clothing exchange), mental health counseling, family medicine, addictions medicine, as well as accompaniment to appointments.

In British Columbia, Raymond and Belanger completed a qualitative study of community-based treatments provided to young adults who were FAS/E. Strategies investigated included: circles of support, lists, memory and organizational aids such as calendars, tracker systems and homework books, and goal setting and planning tools. The strategies showed potential, depending on the time commitment and the skills of the volunteer mentors (often parents) who attempted to implement them. Raymond and Belanger contended that support services should not be linked to IQ, as if often the case, but rather should be related to the level of dysfunction or maladaptivity exhibited by the client. Many FAE clients possess normal IQs, but are seriously dysfunctional, because of the neurotoxic effects of alcohol (to which they were exposed parentally) on selective parts of their developing brains, resulting in organic brain impairment. Such dysfunction or maladaptivity is best measured by the Vineland Adaptive Behavior Scales[126] and the Scales of Independent Behavior Resided,[127] rather than by any IQ test. A paradox arises because, at a superficial level, individuals with FAE may appear and sound normal, and test normal in IQ (or at least higher than the usually 70-IQ benchmark for receipt of government support services), but, be maladaptive, nevertheless, in everyday functioning, to the extent of requiring intensive, ongoing supports.[128]

The David Livingstone Community School in Winnipeg, MB, provides a partial answer to some of the problems facing children with FASD, through currently segregated, and, hopefully, in future, integrated school programs. The staff employs strategies and practices found by them to be effective in educating such children.[129] The programs, from kindergarten to grade six, are organized around concepts of providing an *external brain*.[130] External brain, coined by Dr. Sterling Clarren, refers to the use of capable, personal mentors and effective memory aids to help FASD individuals compensate for memory deficits, and other mental gaps, as well as lack of impulse control, and poor judgment.

[125] *Supra* note 18 at 270-275. (Streissguth, *A Guide for Families and Communities*)

[126] Sparrow, S.; Balla, D.; & Cichetti, D. *Vineland Adaptive Behavior Scales (VABS)* (American Guidance Services: Circle Pines: MN, 1984).

[127] Bruininks, R. H.; Woodcock, R.; Weatherman, R., and Hill, B. *Scales of Independent Behavior Revised* (Scarborough, ON: Nelson Thomson Learning, 1996).

[128] Raymond, M. and Belanger, J. Literacy-Based Supports for Young Adults with FAS/FAE. (132 p.) British Columbia: Joint Projection of the National Literacy Secretariat, Human Resources Canada, Minister of Advanced Education, Province of British Columbia. Retrieved October 2, 2002, from the World Wide Web: http://www.nald.ca/fulltex/lbsupport/Doc/pdf/.

[129] School of Hope: Teaching Kids with Fetal Alcohol Syndrome, retrieved from the World Wide Web, September 12, 2003: http://www.come-over.to/FAS/schoolofhope.htm.

[130] External Brain, retrieved from the World Wide Web September 12, 2003: http://www.come-over.to/FAS/externalbrain.htm.

April 1, 2001, KidsFirst was initiated in Saskatchewan. The program is based on research evidence that indicates that the early years, particularly birth to age three, are critical in determining the future outcomes of children—their long-term social, emotional, cognitive, and health functioning. When children do not get a good start, the long-term consequences include: poor educational achievement, low employment levels, low income levels, increased reliance on social support systems, increased involvement with the justice system, and poor health outcomes. When children receive a good start, they are more likely to become well functioning, contributing members of society.

KidsFirst is Saskatchewan's response to the federal funding commitment following the Federal/Provincial/Territorial Agreement reached in September, 2003. KidsFirst direction and framework is provided by the Early Childhood Development Branch through the Departments of Learning, Health, and Community Resources and Employment. The program is implemented and delivered at the local level by third party agencies. KidsFirst supports families in vulnerable circumstances to become stronger families, by enhancing parenting knowledge, providing support, and building on family strengths.

KidsFirst in Saskatchewan is a voluntary program that targets vulnerable families found in community clusters. There are nine KidsFirst sites in the province: Meadow Lake, Nipawin, North Battleford, Yorkton, Moose Jaw, Prince Albert, Regina, Saskatoon, and all of Northern Saskatchewan. Only vulnerable pockets within the nine sites fall under the aegis of KidsFirst. This is so because when families are living under difficult circumstances, such as low income or exposure to abuse, caring for children becomes even more problematic.

To be eligible to be part of KidsFirst, in addition to serviced location, families must have at least one child under the age of 5 years. KidsFirst includes a number of key components: prenatal referral and support, universal in-hospital screening, home visiting, mental health and addictions services, enhanced early learning, and childcare and family support opportunities. The prenatal component focuses on prevention of FASD and reducing the impact of alcohol on pregnancy. Basically, this component is a prenatal outreach program designed to support pregnant women using drugs and alcohol, by providing them with nutrition supplements and enhanced prenatal supports. The intent is to reduce the impact of alcohol on the fetus and to engage the women in addictions treatment so that their subsequent pregnancies are alcohol-free.

The universal, hospital-based, screening program for newborns and their families is used as a first indicator of vulnerability. The home visiting component includes once a week visits. Mental health and addictions services are specifically dedicated to KidsFirst clients, as well being provided in a non-traditional manner. The community component of KidsFirst is provided through partnerships with local agencies for such services as: enhanced early learning, childcare opportunities, and supports such as literacy, parenting skills, further education, food, security, and transportation. KidsFirst works with families to help them address many of the determinants of health.[131] Hopefully, Kids First will provide its clients with a better start in life, and will be able, incrementally, to extend its mandate province-wide, without age limitation, in order to accommodate all families with children, young persons, and dependent adults with extensive needs such as FASD presents.

An Interdepartmental Committee has been structured by the Government of Saskatchewan with the task of framing a strategic plan to provide integrated services for individuals with FASD. Participating departments include: Health, Learning, Community Resources and Employment, Justice, Corrections and Public Safety, and Aboriginal and Intergovernmental Affairs. "A Strategic Plan," dealing with prevention, assessment, support, and training is due April, 2004. An interim report, "Results from FASD Discussion, Summary Report," is to be completed by February, 2004. The interim report will deal with the results of community consultations, meetings, surveys, and conference forums held since the committee was structured in 2002. Health Canada also has fashioned a National FASD Framework. [132] The Canada Northwest FASD Partnership, comprised of Alberta, Saskatchewan, Manitoba, Yukon, Northwest Territories, Nunavut, and British Columbia, co-operates inter-jurisdictionally on prevention and treatment issues. These initiatives are critical as FASDs require interagency

[131]Telephone Conversation, January 7, 2004, and e-mail communication with Elaine Clark, Sask. Learning Early Child Development Unit, January 19, 2004, eclark@sasked.gov.sk.ca. KidsFirst web-site, retrieved January 7, 2004, from the World Wide Web: http://www.sasked.gov.sk.ca/echild/ecd_annual_report_2001-2 pdf.

[132]Telephone conversation with Wanda Lyons, Member of Interdepartmental Committee on FASD, January 7, 2004; and e-mail communication with Pat Inglis, Department of Health, Chair of Interdepartmental Committee on FASD, January 19, 2004. A meeting has been requested.

and inter-jurisdictional supports, due to the interdisciplinary nature of their disabilities which transcend boundaries.[133] Specialized strategies for FASDs are required, because of the distinctive nature of their secondary disabilities, and the gravity of the problems they may face. Strategies need to be implemented quickly, before more disabled young persons become marginalized and/or criminalized because of their disabilities; such a goal requires cooperative effort.

Evolving evidence, although elusive, seems to indicate that including the spiritual dimension is effective in producing a balanced life. *Generation at Risk: Growing up in an Era of Family Upheaval*, a study by sociologists Paul Amato and Alan Booth,[134] found *inter alia* that the children of families who practiced a religion were more settled and stable, had more positive self-concepts, and were more optimistic about their futures, even in today's uncertain times, than were the children in a control group. One would expect similar results from the practice of traditional Aboriginal beliefs. The spiritual dimension might be expected to play a more critical role for Aboriginal youth, who, because of their heritage rooted in colonial practices such as residential schools and child welfare policies, face cultural as well as family breakdown. In a related vein, Ralph Mason, at the Regional Psychiatric Centre in Saskatoon, found support for the healing nature of the traditional Aboriginal Sweat Lodge Ceremony among sexual and violent offenders (albeit, not formally diagnosed with FASDs).[135] In a series of studies, including the landmark study, "Cultural Continuity as a hedge against suicide in Canada's First Nations," Chandler & Lalonde[136] discovered lower suicide rates in First Nations communities in British Columbia where culture and self-determination were strong. Young persons in these communities felt that there was a future for them and their way of life, over which they had some control.

Restorative Circles Initiative (RCI) is a new pilot project in Saskatoon sponsored by the Department of Justice Canada - Youth Justice, subsequent to the implementation of the YCJA and its emphasis on reducing the number of young persons in custody, and with the support of the local King George Community & School Association. The Director, Don Meikle, thinks that the program has potential for dealing with FASD youth. Inclusive of family and community, RCI assists youth involved with the justice system to find an alternative method of dealing with problems, through healthier life styles and better choices, while maintaining respect and dignity for themselves and others. The circles that RCI structures are based on the values of restorative justice, and may be either pre-sentence circles (with victims involved), or post-custody circles (to support the youth during a period of rehabilitation and reintegration into the community). Attending at the circles may be the youth and victim(s), their families, Elders, volunteers from the community, justice staff, and a judge or facilitator. Pre-sentence circles are ordered by a judge seeking recommendations for sentencing and in search of resources to support the sentencing option. Volunteer mentors, trained by RCI, particularly positive peer roles models, are found to be effective with FASD youth and become part of the integrated, interagency team selected to work with the youth. The ideal is for the mentor to provide ongoing follow-up with the youth, particularly following custody, for a minimum six-month period. The mentor can link the youth up with members of the integrated service team as required. A great need exists for such programs throughout Saskatchewan.[137]

[133] Canada Northwest FASD Partnership. Retrieved January 28, 2004, from the World Wide Web: http://www.faspartnership.ca/aboutus/page.cfm?pg=index.

[134] Amato, P. & Booth, A. *Generation at Risk: Growing up in an Era of Family Upheaval* (Cambridge, Mass.: Harvard University Press, 1997).

[135] Mason, R. *The Healing of Aboriginal Offenders: A Comparison Between Cognitive-Behavioral Treatment and the Traditional Sweat Lodge Ceremony,* Unpublished Masters' Thesis, University of Saskatchewan, Saskatoon, 2000.

[136] Chandler, M. J. & Lalonde, C.E. "Cultural Continuity as a Hedge Against Suicide in Canada's First Nations" (1998) 35(2) Transcultural Psychiatry, 193-211; and Chandler, M. J., Lalonde, C.E., & Sokol, B. "Continuities of Selfhood in the Face of Radical Development and Cultural Change. In L. Nucci, G. Saxe, E. Turiel (Eds.), *Culture, Thought, and Development*, pp. 65-84 (Mahwah, NJ: Lawrence Erlbaum Associates, 2000).

[137] Pamphlets, Project Description, and Interviews with Restorative Circles Initiative, 206-119 4th Avenue South, Saskatoon, SK, S7K 5X2.

4. SOCIAL CONSTRUCTION OF FASD AND ITS IMPLICATIONS

Fetal alcohol spectrum disorders (FASDs) to a large extent are socially constructed.[138] It is illuminating, therefore, to discover the perspectives of differently situated observers regarding FASDs, including the viewpoints of affected individuals. Because of the correlation between law breaking and the presence of FASDs in individuals, there tends to be a moral undertone to the social-construction of the condition.[139] To observe whether, with effective intervention for FASDs, any tendency of the variously situated observers to perceive the illness as a moral disorder will be attenuated or even eliminated, will prove intriguing.

The moral dimension was originally connected (and continues to be connected) to the etiology of the disease, through repugnance aimed at maternal consumption of alcohol during pregnancy and resultant fetal damage. Associated judgmental attitudes have affected access to treatment adversely for both addicted mothers and affected offspring. Presumption of personal autonomy or free will, on the part of an expectant mother, to abstain from alcohol consumption is questionable, as explained previously. Marginalized women deemed to be at risk are subject to the surveillance of the Foucauldian medical gaze,[140] a glare more penetrating than any scrutiny given liquor manufacturers, government regulators, or root causes of the marginalization of affected persons:

> [T]he patient becomes subject to the medical gaze. For Foucault (1975), it is through the medical gaze that the patient's body is constructed as a particular archetype of illness. The medical gaze is a product of a dominant discourse in scientific medicine that champions the importance of expert medical practitioners using visual cues to assess and monitor patients' bodies. [Foucault, M. (1975) *The Birth of the Clinic: An Archaeology of Medical Perception*. New York: Vintage.]

Rather than transfixing victims, the "medical gaze" should consider, with a view to their elimination, barriers facing pregnant women seeking treatment of their addiction, including: psychological barriers of shame, fear, and alienation; unavailability of childcare; fear of having children apprehended were mothers to admit to being addicted; lack of after-care; sociographic factors such as costs of travel to treatment; the powerful stigma attached to being pregnant and addicted; and barriers related to treatment programs, such as whether such programs are woman-centered and culturally appropriate, and taking into account any impact of negative past experiences with similar programs.[141]

A case occurred where an expectant, addicted mother (with three other children in care, two of whom were FAS affected) was forcibly detained in a hospital to protect her unborn child. The Supreme Court held such detention illegal, as the fetus was not a legal person, and the detention order would impinge on the mother's right to liberty.[142] Ironically, the very fetus the Crown was seeking to protect through the detention order could have been legally aborted by that mother under Canadian law had she so desired. The mother, Ms. G., had sought treatment voluntarily prior to the detention order, but when it was not available had succumbed to her addiction. Once hospitalized, she complied of her own volition with the detention order; when it was withdrawn, she remained in hospital until after the baby's birth. Her baby was born, apparently unharmed. With 24 hour in-home support, she was able to maintain her sobriety and to care for the child.[143]

[138] *Supra* note 15. (Auton, BCCA, 2002) at para. 51: Writing for the majority, Madam Justice Saunders describes Autism Spectrum Disorders (ASDs) as socially constructed handicaps, rather than the result of adverse effects discrimination, the term used to describe the dynamics of the discriminatory effect in *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624.

[139] Armstrong, E.M. "Diagnosing Moral Disorder: The Discovery and Evolution of Fetal Alcohol Syndrome" (1998) 47(12) Soc. Sci Med. 2025-2042.

[140] Foucault, M. *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Vintage, 1975), cited in Lupton, D. "The Social Construction of Medicine and the Body" in C. Bird (Ed.), *The Handbook of Medical Sociology* (New Jersey: Prentice Hall, 2000), 50-63 at 55.

[141] *Supra* note 114. Tait. C. *A Study of Services Needs of Pregnant Addicted Women in Manitoba* (Winnipeg, MB: Prairie Women's Health Centre of Excellence, 2000).

[142] *Supra* note 116. *Winnipeg Child and Family Services, Northwest Area v. D.F.G.* (1997), 152 D.L.R. (4th) 193 S.C.C.

[143] This information pertains to the time period of the Court's jurisdiction, and to the extent of the information available to the Court.

The Royal Commission on Aboriginal Peoples recorded the following testimony, in **vol. 3, Gathering Strength**[144] at pages 132-33:

> Children with FAS or FAE are often difficult babies, especially if they are withdrawing from the alcohol that surrounded them in the (womb). If the mothers are still actively abusing alcohol, these children are often subject to attachment breaks, abuse, and/or neglect, and they often become involved with the child welfare system as foster or adopted children.
>
> . . . . .
>
> They are hard to care for, their disability is not understood, there are many peer and social pressures, no skills to fall back on . . . Currently we believe many adults (who were born) with FAS/FAE are either on the street or in jail. [page227] (*cited in D.F.G. at p. 37*)

Personal autonomy in women's lives has been eroded by the stress and trauma of colonization, and its paternalistic, misogynistic practices. Aboriginal women have been affected particularly adversely by restrictive, sexist legislation and policy, which has tended to exclude them differentially from status, band membership and governance, and concomitant benefits. As well, interference with the exercise of their maternal function that originated in residential schools continues with current child protection policies.[145] Resultant devaluation and loss of roles has rendered some of them rootless, subject to domestic violence at home and to racism and sexism in the larger community. Stressed, traumatized and marginalized, such women become vulnerable to alcohol abuse and addictions.[146]

Potential social value of research and education in this area lies in its possible positive impact on public opinion and policy resultant from greater understanding of individuals with fetal alcohol conditions and their need, not for incarceration, nor "boot camp" scenarios, but rather for holistic, community-based treatment. Community supports consistent with both the Aboriginal model and non-judgmental understanding of those with FASDs, their families and culture, are essential to produce more healthy individuals living within healthier communities, and to maximize the life adjustments of all concerned. Understandings so gleaned might extend to other individuals with other disabilities or mental disorders, eliminating at least some of the stigmatizing and marginalization to which they are subject, and reducing the cycle of crime experienced by segments of this population.

For FASDs, complicated diagnostic procedures, protocols, and standardized templates exist to measure precisely each facial and structural anomaly noted, and fix it at a certain growth percentile: for example, to be FAS, the palprebal fissues (width of eye openings) must be 2 standard deviations below normal for age,[147] and pictoral Likert scales are used for rating the thinness of the vermilion border of the upper lip when lips are closed with no smile, and the smoothness of the philtrum.[148] Also, the United States Institute of Medicine recommends a team approach to diagnosis of FAS, including *inter alia* participation of a neuropsychologist, and a pediatrician, and ideally a physical therapist, occupational therapist, speech-language pathologist, and social worker. For court-ordered assessments, to determine fitness for trial or the exculpatory existence of a mental disorder, there are elaborate diagnoses required. Paradoxically, few funds remain for treatment, including paraprofessional mentoring programs which are relatively low cost. Ironically, a patient, diagnosed and possibly stigmatized by a label, finds little treatment available to attenuate symptoms and perhaps reduce related stigmatization. Many

[144](Ottawa: The Commission, 1996).

[145]The *Saskatchewan Children's Advocate Annual Report, April 2003*, indicates that as of March 31, 2002, 3300 children were in care of the Minister of Social Services under the *Child and Family Services Act*, and a further 1042 children were in care of the Minister but receiving services from the Indian Child & Family Service Agencies (ICFS) through the aegis of Indian and Northern Affairs. The Saskatchewan Children's Advocate Office's *Children and Youth in Care Review: Listen to Their Voices, Final Report*, April, 2000, Table 2, page 38, reports percentages of children and youth in care as of March 31, 1999, according to the following categories: 6.1% Metis, 2.8% Non-Status, 57.8% Status, 2.3 % unknown, and 31% Non-Aboriginal, out of a total of 3030 in care, excluding 179 cases serviced by ICFS.

[146]Hamilton, A. & Sinclair, C., "Chapter 13, Aboriginal Women," *Report of the Aboriginal Justice Inquiry of Manitoba, Volume 1: The Justice System and Aboriginal People* (Altona, MB: D.W. Friesen and Sons Ltd.: 1991) at 475-497.

[147]Koren, G., Nulman, I., Chudley, A.E., & Loocke, C. "Fetal Alcohol Spectrum Disorder," *Canadian Medical Association Journal*, 2003, at p. 1181.

[148]*Supra* note 63. (Astley & Clarren)

FASDs experience their first encounter with diagnosis through the Criminal Courts; at this juncture, it is generally too late for optimum early intervention. With the paucity of treatment availability of any kind, it is the proverbial "too little, too late." The status quo is costly and ineffective; certainly, there is a need for early diagnosis and screening, but also for effective early intervention and treatment, avoiding costly (in both human and monetary terms) encounters with the Criminal Court wherever possible. The curious lack of effort directed at treatment has been commented upon by the United States Institute of Medicine's Committee to Study Fetal Alcohol Syndrome:

> There has been a curious lack of enthusiasm for targeted efforts directed at the prevention of secondary disabilities. The view that intervention may not be useful in children affected by alcohol is inconsistent with the attitude taken toward other groups of high-risk and disabled children. Few systematic attempts have been made to intervene with alcohol-affected children to test the possibility that such strategies would be effective in producing more positive outcome.[149]

Inexplicably, affected children, exposed *in utero* involuntarily, nevertheless suffer stigmatization, aggravated by the scarcity of treatment services. Beyond blaming affected individuals and, particularly, their mothers, little has been done to alleviate causal factors, such as social conditions. Alcohol itself has been "medicalized," appearing seemingly out of nowhere in the discourse, the "innocent agent" consumed by a so-called "blameworthy" mother whose consumption it is that causes damage to her fetus. Manufacturers and government regulators of this alcohol are almost excluded from the blaming discourse, though they benefit from the production and sale of alcohol to the tune of billions of dollars annually.[150] The Crown profits without requiring the industry to use product warning labels, or without adding product warning labels themselves, to an intoxicating, addictive, and teratogenic product.[151] Perhaps the etiology itself of FASDs is socially constructed; if so, it requires considerable deconstructing, to eliminate the misplaced moral dimension that presents a formidable barrier to treatment of mothers and their affected children. A moral dimension is best removed altogether from scientific/medical discourse, to be replaced by a non-judgmental, pragmatic, approach to solutions.

Susan Sontag[152] asserts that there is nothing more punitive than giving a disease a moralistic meaning. She discusses the "blaming of the victim" that occurred with HIV/AIDS; initially, sufferers were seen as gay men, perceived to have engaged in risky activities, who had thus "authored their own misfortune." Such stigmatizing attitudes delayed the search for treatment and cure.[153]

Equity issues such as class, race, gender, age, sexual orientation, and disability may operate to deny access to appropriate treatment.[154] Many FASDs are triply disadvantaged in being children, disabled, and marginalized. They cannot advocate effectively for themselves. To compound matters, many of them in care or child protection, have been moved from home to home, without a parent or concerned mentor to advocate for them. Even if not in care, if their mothers are marginalized, suffer various forms of gender discrimination, and face barriers to treatment for their substance abuse and addictions, effective maternal advocacy for children concerned is virtually eliminated.

[149] *Supra* note 53. Stratton, K., Howe, C., & Battaglia, F. (EDs.) Committee to Study Fetal Alcohol Syndrome, Division of Biobehavioral Sciences and Mental Disorders, Institution of Medicine. *Fetal Alcohol Syndrome, Diagnosis, Epidemiology, Prevention, and Treatment* (Washington, D.C.: National Academy Press, 1996) at 12.

[150] Statistics Canada, *Beverage and Tobacco Products Industries* 1988, Annual, Industry Division, November, 1991, Table II. The use of alcohol beverages in a variety of settings, is firmly entrenched in Canadian society. Also the production and sale of beer, spirits and wine comprise major industrial activities in Canada, as in other countries. Figures published by Statistics Canada show that sales of Canadian beer, spirits and wine in Canada in 1988 amounted to a total of more than 7.6 billion dollars; sales of Canadian beer, at almost 4.6 billion dollars, accounted for more than half this total. When imported products are included, the total value of Canadian sales of alcoholic beverages for 1988 rises to almost 9.6 billion dollars. In Standing Committee on Health and Welfare, Social Affairs, Seniors and Status of Women, 34th Parliament, 3rd Session, No. 10-22, index 1992-1993, Foetal Alcohol Syndrome, A Preventable Tragedy, (Ottawa: Queen's Printer for Canada, 1988-1992). Note: presently, similar statistics are indicated only in Kilolitres, not dollars, making such comparisons difficult.]

[151] Note: The present writer does not argue for prohibition, but for warning labels on alcoholic products, and for nonjudgmental, effective treatment of addicted mothers and their affected children. A suggested warning label might read: "Drinking alcohol while pregnant can cause birth defects."

[152] *Illness as Metaphor/AIDS and its Metaphors* (New York: Anchor, 1989) at p. 58.

[153] *Ibid.*

[154] Ferguson, L.G. *Deconstructing Fetal Alcohol Syndrome: A Critical Inquiry into the Discourse around Alcohol, Women, Ethnicity, Aboriginals and Disease,* Unpublished Master's Thesis, Carleton University, Canada, 1997.

5 RIGHTS DISCOURSE

5.1 Section 15 of the *Charter of Rights and Freedoms*: Equality

A decision of Saskatchewan Provincial Court Judge Mary Ellen Turpel-Lafond, in which she attempted to mandate community-based treatment for a young person affected by FASD, served as a catalyst for this aspect of the research. The decision was overturned on appeal,[155] absent the admissibility, for procedural reasons, of a s. 15 *Charter of Rights and Freedoms*[156] challenge. The role of s. 15 of the *Charter* in mandating treatment for FASD affected individuals to accommodate their disabilities remains moot, pending further litigation. What is patently clear and merits repetition is that for individuals with mental disorders such as FASDs, carceral placements are not appropriate, as they render such individuals subject to negative peer influences, victimization, and consequent deterioration in their mental states, as discussed in Section 1.1.

5.2 The Law Analysis: Context and Dignity

The framing of the s. 15 *Charter* argument, extrapolated in the direction indicated by the Supreme Court (*Law v. Canada*, [1996] 1 S.C.R. 497), is a compelling route for mandating access to treatment essential for persons with FASDs.[157] The s. 15 analysis involves a broad, contextual study, informed by root causes, rather than a narrow, reductionist determination. Many factors related to the social, economic, political, and historical conditions and situations of persons with FASDs may be taken into account in such analysis, as well as the present circumstances and future prospects of those affected. Section 15(1) of the *Charter*, the particular subsection of s. 15 pertinent to the analysis, states:

> 15(1) Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Those with FASDs may qualify under enumerated *Charter* grounds of disability (FASDs are both a mental and physical disability), age (especially if they are children, as children are usually more vulnerable than adults), and race (if non-white). The general purpose of s. 15(1) is to protect human dignity, which discrimination demeans (*Law, supra*). In fact, an act is not to be considered discriminatory under s. 15(1) unless it does demean dignity. Furthermore, the discriminatory act must be either legislative, or taken under statutory authority; discriminatory acts of a private person, private corporation, or other non-governmental actor, are not considered under the *Charter*. As health care providers, educators, and social service personnel, all act under statutory authority, were any of them to deny treatment to an FASD individual, that denial of treatment may be discriminatory under s. 15(1).

Aboriginals, the majority of FASDs, have suffered historical disadvantage through colonization. Excesses of the whiskey trade, followed by blanket Crown prohibitions of alcohol, are factors contributing to consumption patterns of binging and excess. That Aboriginal people continue to live subject to marginalizing socio-economic factors is demonstrated by social health indicators: diabetes, tuberculosis, heart, lung and kidney disease, addictions and fetal alcohol, youth suicide, infant mortality rates, longevity statistics, mental health, accidents

[155] *R.* v. *L.E.K.*, [2000] SKCA 48.

[156] *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act*, 1982 (U.K.), 1982, c. 11.

[157] *Supra* note 1. A full analysis of this process was attempted in the author's LL.M. research, and is ongoing as insights and litigation emerge. For a more thorough analysis, please refer to the author's thesis, *Barriers to Implementing Holistic, Community-Based Treatment for Individuals with Fetal Alcohol Conditions*.

and injuries, environment health, communicable diseases, education and employment levels, and others. These deleterious results reflect the intergenerational effects of colonization on Aboriginal peoples' lives. Residential schools, the sixties scoop, and subsequent child protection policies form part of this pattern. Many Aboriginal children, and other children with FASDs, are, or have been, subject to child protection orders or arrangements.[158] The state has a greater duty of care to such children than to others, an obligation deriving from the ancient *parens patriae* jurisdiction of the Court. This doctrine is based on the premise that the law has a special duty to protect and advantage dependent children (and other dependent individuals). Such children, unlike other children, have no one, save the court, to advocate for them, and are not of age or capacity to advocate for themselves.

Other disabled children, such as those with Autism Spectrum Disorders (ASDs) may be in protective care, but to a lesser degree. They more likely come from middle class homes, with parents, who because of income and education, are able to advocate for them. In a recent civil litigation in B.C.,[159] some parents of ASDs were able to mount a successful s. 15(1) claim under the *Charter* to have intensive early behavioral intervention funded by the province for their children.[160] Similar litigation is ongoing for ASD children in Ontario.[161] Favourable decisions may serve as precedents for FASDs seeking similar treatment, and would be included as such in the s. 15(1) analysis.

Treaties with Indians are an important constituent of the contextual factors to be considered in a s. 15(1) analysis for FASDs, for treaty beneficiaries who have been affected adversely by fetal alcohol exposure. Treaties were to be road maps to provide opportunities for treaty beneficiaries, including just distribution of goods, liberty, and opportunity. Particularly relevant is the alcohol ban contained in Treaties 1 through 6; Indian signatories and their missionary advocates wanted to protect Aboriginal people from the ravages of alcohol experienced during the whiskey trade which immediately preceded most adhesions to the numbered treaties. These treaty alcohol bans, recognized and affirmed in s. 35 of the *Constitution Act, 1982*, as part of the *Canada Act, 1982*, were not properly enforced by the Crown over the years. Thus Aboriginal children were involuntarily exposed to the teratogenic effects of alcohol *in utero*.

Treaty alcohol bans differ fundamentally from the blanket bans unilaterally imposed by the Crown under the *Indian Act*. Especially in the face of Crown infractions, Treaty alcohol bans continue to be upheld by the Courts.[162] Blanket bans, unilaterally imposed by the Crown, lost legal effect many years ago.[163]

The epidemiological aspect of in utero transmission of FASD is well documented, and is attributable, in part, at least, to Crown action or inaction. By not mandating warning labels on liquor bottles, by not providing effective treatment for those damaged by alcohol, and by not enforcing (and even themselves breaching)[164] constitutionally protected treaty alcohol bans, the Crown has not mitigated its responsibility to those adversely affected by its acts or omissions.

[158]Greschner, D. and Lewis, S., "Medicare in the Courts: *Auton* and Evidence-Based Decision-Making," Canadian Bar Review, publication pending. Note: two of the following sources were first cited and discussed in Greschner and Lewis' article. Habbick, B. F. et al, "Foetal Alcohol Syndrome in Saskatchewan: Unchanged Incidence in a 20-year period" (1996) 87 Can. J. Public Health, 204-7. Only 25.6% of children with FAS/E lived with their biological parents when last seen at a provincial child development centre. In E. A. Loney et al, "Hospital Utilization of Saskatchewan People with Fetal Alcohol Syndrome" (1998) 89 Can. J. Public health, 333-335, 88% of the hospitalized people with FAS/E were Aboriginal.

Supra note 145: According to the Annual Report of the Children's Advocate, in Saskatchewan, as of March 31, 2002, 3300 children were in the care of the Minister of Social Services under the *Child and Family Services Act*, and a further 1042 were in the care of the Minister receiving services from Indian Child & Family Service (ICFS) Agencies under the aegis of Indian and Northern Affairs. In a 1999 special study by the same agency, 3030 children and youth were in care comprised of 6.1% Metis, 2.8% Non-Status, 57.8% Status, 2.3% unknown, and 31 % Aboriginal, excluding an additional 179 cases handled by ICFS.

[159]*Supra* note 15. *Auton (Guardian ad litem of) v. British Columbia (Attorney General)*, [2002] BCCA 538.

[160]*Auton (Guardian ad litem of)* v. *British Columbia (Minister of Health)*, [1999] B.C.J. No. 718 at para. 8-14. The form of early intensive behavioral intervention (IBI) requested by the petitioners was the Lovaas Autism Treatment (LAT). Numerous jurisdictions, including Alberta, Prince Edward Island, England, and a number of states in the United States, have recognized the LAT as an appropriate therapy for autism. The treatment is based on the work of Ivar Lovass, a psychologist at UCLA in California; he developed his method in the seventies and published the results of his research in 1987. The basic premise of his treatment is that people with autism can be taught, on a one-to-one basis, the skills that they lack, primarily through rewarding appropriate behaviors. The treatment is very intensive, about 40 hours a week, and to be effective, must be employed early in the child's life. Although the treatment costs $45,000.00 - $60,000.00 per year per child, Dr. Lovass estimated (1987) that the savings for each child would be $2 millions U.S. in care over the course of his or her life. Without effective treatment, the majority of autistic children are severely impaired in intellectual, social and emotional functioning, and require extensive care throughout their life span.

[161]Clough (Litigation guardian of) v. Ontario, [2003] O.J. No. 1074 (OntSupCtJus.); and Lowrey (Litigation guardian of) v. Ontario, [2003] O.J. No. 2009 (OntSupCtJus).

[162]*R. v. Wolfe*, [1995] S.J. No. 502 (SKCA).

[163]*R. v. Drybones* (1969), 9 D.L.R. (3d.) 473 (S.C.C.).

[164]*Supra* note 162. Alcohol has been illegally used as an inducement to entrap Indians into selling wild meat to undercover agents in wildlife sting operations on reserve land, as in *R. v. Wolfe, Supra* note 162. Charges were stayed against the Indian hunters in *Wolfe* due to the violation of the treaty alcohol ban.

The essence of the "dignity" aspect of s. 15 is the marginalization and exclusion from society disabled people suffer, absent adequate treatment through accommodation of their disabilities and differences.[165] Without accommodation that could attenuate their secondary characteristics, FASD individuals may well be subject, not only to rejection and institutionalization, but also to the harsh consequences of incarceration, the most extreme form of exclusion and stigmatization. Because of the organic brain impairment such individuals suffer due to the prenatal teratogenic effects of alcohol, they are unable to appreciate fully the consequences of their actions. They may impulsively repeat inappropriate actions, becoming subject to escalating carceral dispositions.

5.3 Crown Justification Under Section 1 of the *Charter*

Governments may attempt to justify infringing *Charter* rights, according to the provisions of section l of the *Charter*:

> *The Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

Thus, once a *Charter* right to treatment is established by FASD claimants, it is subject to limitation by the Crown under section l. The crux of this limitation for disability cases, like *Auton (supra* note 15) and *Eldridge (supra* note 165), and by implication, FASD claimants, focuses on whether or not the denial of treatment constitutes only a minimum impairment of the right. Minimum impairment means that the government has made reasonable accommodation to the point of "undue hardship." Pursuant to *Law*, undue hardship and the "dignity" analysis may overlap in the sense that any accommodation short of ameliorating the marginalization and exclusion of FASDs would not be justified under either analysis.

An additional factor militating against Crown justification under section 1 is the commitment made by Canada to the United Nations *Convention on the Rights of the Child*[166] (CRC). Articles 23, 24 and 40(3) & (4) of CRC uphold the right of all children to the highest standard of health care, extending that right with particular attention to the needs of mentally or physically disabled children. Such needs would include rehabilitative treatment to promote both self-reliance and full participation in the community, and assured access to education, training, health care services, rehabilitation services, recreation, and preparation for employment. Needs of child offenders are also to be considered. These would include access to the same services as other children, and, as a priority, access to dispositions other than institutionalization.

The Court may require cost-benefit analyses data and empirical measures of efficacy of treatment, in order to justify curial intrusion into the executive aspect of government. In mandating that governments provide funding for treatment, courts first must be certain that a serious *Charter* breach has occurred, and that such a breach cannot be justified by reasonable limits. Although no scientifically proven method of treating FASDs exists, ameliorative practices are recommended by experts in the field.[167] Cost-benefit analyses indicate the folly of persisting with the status quo; costs of ameliorative treatment are more than offset by the savings of not having to pay for lifelong care and institutionalization or incarceration of FASDs. The case for mandating voluntary treatment of FASDs is compelling, given the Crown's noted complicity in the sale and regulation of alcohol, its breach of the duty to warn effectively of the dangers of alcoholic products through warning labels on the products, and its breach of the constitutionally protected treaty alcohol ban, now part of the supreme law of Canada.[168]

[165] *Eldridge v. British Columbia,* [1997] 3 S.C.R. 624.

[166] G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), ratified in Canada in 1992.

[167] *Supra* note 96. Roberts, G. and Nanson, J. *Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy* (Ottawa: Health Canada, 2000).

[168] S. 52, *Constitution Act,* 1983: The Constitution of Canada is the supreme law of Canada, and any law that is inconsistent with the provisions of the Constitution is, to the extent of the inconsistency, or no force or effect.

5.4 Jurisdiction over Health Care

Jurisdiction over health care is tripartite in nature, possessing a federal, provincial, and Aboriginal component:

> Health is not a single matter assigned by the Constitution exclusively to one level of government. Like inflation and the environment, health is an "amorphous topic" which is distributed to the federal Parliament or the provincial legislatures depending on the purpose and effect of the particular health measure in issue. . . . The federal Parliament has used its spending power to impose national standards for hospital insurance and medical care programmes as a condition of federal contributions to these provincial programmes.[169]

Under the *Constitution Act, 1867*,[170] the province has authority under s. 92(16), local and private matters (public health); s. 92(13), property and civil rights (food and drugs, and professional regulation); and s. 92(7), authority over hospitals. Aboriginal peoples assert authority pursuant to s. 35 of the *Constitution Act, 1982*, under the aegis of such protected rights as self-determination, and the medicine chest provision of Treaty 6. Jurisdiction over Indians and Lands for Indians was conferred solely upon the Federal Government, under s. 91(24) of the *Constitution Act, 1867*, but may be devolved to the province, or to bands or treaty areas.

A case in point is the 1994 tripartite agreement that the Treaty 4 area entered to build and maintain a hospital at Fort Qu'Appelle, Saskatchewan. The tripartite agreement is among the federal government, provincial government, and the File Hills Qu'Appelle Tribal Council. Unlike other hospitals or health centres in the province, the Fort Qu'Appelle Indian Hospital is not owned by the provincial government, but pursuant to the tripartite agreement, is owned by a holding company that reports to the File Hills Qu'Appelle Tribal Council. A ten million dollar fund from the federal government was used for capital outlays, while the province, through the District Health Board, contributes to operating costs. The hospital models a holistic approach to wellness, attempting to provide an array of both institutional and community-based programs and services, including: counseling, traditional medicine, traditional diet counseling, liaison services, and respite. Both First Nations, and non-Aboriginal representatives from neighbouring communities are members of the Fort Qu'Appelle Indian Hospital Board Inc., established by the Tribal Council to manage the facility.[171]

Current FASD and ASD cases can be distinguished from *R. v. Turpin* (1989),[172] *R. v. S. (S.)* (1990),[173] and *Haig v. Canada* (1993)[174] in that these earlier cases mounted s. 15 Charter challenges on the basis of differential treatment due to province or place of residence. FASD and ASD claimants do not; their claims rest on s. 15(1) of the *Charter* as well, but are based on the enumerated ground of discrimination due to disability, not on the analogous ground of place of residence. Under a federal system, however, place of residence raises some considerations, even if place of residence is not the basis of the *Charter* claim. Matters coming solely under provincial jurisdiction according to s. 92 of the *Constitution Act, 1867*, may vary from province to province, as was the intent of the constitutional division of powers:

> There can be no question, then, that unequal treatment which stems solely from the exercise, by provincial legislators, of their legitimate jurisdictional powers cannot be the subject of a s. 15(1) challenge on the basis only that it creates distinctions based on province of residence.[175]

[169]Hogg, P. W. (2003). *Constitutional Law of Canada*. Toronto: Thomson Carswell, at s. 18.4.

[170](U.K.), 30 & 31 Vict., c.3.

[171]Fort Qu'Appelle Indian Hospital transferred to First Nations control. Retrieved January 17, 2004, from the World Wide Web: http://www.hc-sc.gc.ca/english/media/releases/1995/ 80e.htm; and Report raises questions about hospital, Saskatchewan Sage Newspaper. Retrieved January 17, 2004, from the World Wide Web: [1989] 1 S.C.R. 1296.

[172]*R*. v. *Turpin*, [1989] 1 S.C.R. 1296.

[173]*R*. v. *S.(S.)*, [1990] 2 S.C.R. 254.

[174]*R*. v. *Haig*, [1993] 2 S.C.R. 995.

[175]*R*. v. *S.(S.)*, [1990] 2 S.C.R. 254, 288, per Dickson, C.J., cited in Hogg at 52.16.

In addition, federal laws need not apply uniformly across the country; rather "province-based" distinctions in *federal* laws can be a legitimate means of promoting the values of a federal system."[176] For these reasons, disabled claimants may elect to name as respondents all three levels of government: the federal, the provincial, and the Aboriginal. If claimants are Aboriginal, all three levels may be named; federal and provincial levels may be named if the claimants are non-Aboriginal. Claimants should be prepared for differences in health care provisions from province to province, differences that may not offend the *Charter*. Therefore, litigation may differ from province to province, based on either the constitutional jurisdiction over its health care of each province, or on province-based distinctions in application of federal laws.[177]

5.5 Section 7 of the *Charter*: Right to life, liberty and security of person

Judge Turpel-Lafond is a First Nations' woman who advocates for marginalized Aboriginal and non-Aboriginal young persons, particularly young persons with disabilities such as FASDs. Not satisfied with the status quo, she pushes the law to evolve in reponse to the needs of the most vulnerable in our society. As a result of a young person with FAS being held Unfit to Stand Trial in R. v. D.B., [2000] SKPC 155, her Court is examining the potential of s. 7 *Charter* litigation for individuals affected by FASDs, in particular those found Unfit to Stand Trial (UST) and dispositions or sentences to which they are subject, or may, due to s. 7, become subject, including absolute discharge.[178] Section 7 of the *Charter* states:

> 7. Everyone has a right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

The young person with FASD in *D.B*. was found UST under s. 2 of the *Criminal Code*.[179] This finding may be subject to appeal, as, at trial, contradictory expert witness testimony was presented as to fitness. The defense, informed by disposition problems previously encountered by USTs under s. 672.54 of the *Criminal Code*, filed a s. 7 *Charter* challenge, to ensure that, were the finding of UST upheld for D.B., rights to life, liberty and security of person would not be breached by a disposition which was not "the least restrictive and punitive," considering therapeutic requirements for alleviating his mental disability. If not considered a significant threat to public safety, D.B., like those with mental disorders found Not Criminally Responsible (NCR) under s. 16(1) of the *Criminal Code*, should be subject to absolute discharge, albeit this option is not permitted in the Code for USTs. Whether resultant automatic, indeterminate detention for USTs like D.B., who due to their permanent disabilities can never become fit, and who are not considered a threat to public safety, is contrary to s. 7 of the *Charter* will be considered in *R*. v. *D.B*. at the local level, and in *R*. v. *Demers*, [2003] S.C.J. No. 58.

However, whatever the disposition, D.B. will require lifelong supports. If not subject to an absolute discharge by means of a *Charter* challenge, he will remain under the jurisdiction of the criminal justice system for the remainder of his life, as his condition is permanent. D.B. is not in the position of someone suffering from a disability like psychosis that medication can alleviate, and who might regain fitness and be able to stand trial, be acquitted, or found NCR and subject to absolute discharge.

Disposition is also an issue for accused with mental disorders who are considered a threat to public safety. The "least onerous and least restrictive disposition," which takes into consideration the need to protect the public, the mental condition of the accused, and the reintegration of the accused into society is to be the order of the day (s. 672.54 of the *Criminal Code*). Dispositions include conditional discharge or a secure hospital disposition (*Ibid*. at ss. (b) and (c)). However, absent therapeutic facilities in the community or in secure hospital

[176] *Supra* note 169 at 52.16, quoting Dickson C.J. in R. v. S.(S.), Ibid. at 289. (Hogg)

[177] *Ibid*.

[178] *R*. v. *T.J.*, [1999] Y.J. No. 57 (Terr. Ct.); and R. v. D.B, [2003] SKPC 155.

[179] R.S.C., 1985.

placements, offenders have languished in administrative segregation in correctional facilities.[180] It was never an intention of the legislation to see such mentally disordered individuals warehoused in penal institutions for extended periods of time. Yet such individuals are at risk of being forgotten, lost indefinitely, and left virtually untreated, in the great maw of the justice system's penal apparatus.

[180] *D.J.* v. *Yukon Review Board*, [2000] Y.J. No. 80.

6. Conclusion

The present writer's goal as researcher, teacher, lawyer, or volunteer advocate, is to attempt to address gaps in the research and in the law, with the purpose of more fully meeting the needs of mentally disordered individuals, particularly those with FASDs. Conflation of contextual, extrinsic, and interdisciplinary aspects of law, medicine, and social sciences will no doubt expedite the achievement of this goal. Empirically-based, qualitative research, employed in the pursuit of equity under the *Charter*, may have a synergistic, transformative effect on society. The result may be a society where inclusion and equity for all become benchmarks. Utopian as it may sound, such transformation is an ideal worthy of dedicated effort. Ultimately, change will require that privilege be transformed into altruism. Foucault's critical gaze does seem to be slowly shifting from marginalized victims, such as FASDs, to the privileged. One wonders how it became otherwise directed. It is truly normal and natural that the gaze should scrutinize the privileged. May it focus there, ever vigilant, until inclusiveness and equity are achieved for all.

Following are specific recommendations to achieve the overall goals expressed for those with FASDS:

- community-based treatment, inclusive of the family, including development and implementation of multi-disciplinary treatment;
- specialized supports throughout the lifespan: early intervention and pre-school, education (one to one), training and employment, job coaches, residential, money management and basic life skills, substance abuse treatment, mental health therapy, social skills and positive role models, and dealing with the justice system and other governmental agencies;
- therapeutic courts;
- alcohol product warning labels;
- effective, culturally appropriate prevention strategies;
- women-centered addiction programs, and supports for women and families;
- more FASD diagnostic services;
- in-home supports for families, rather than foster care;
- screening services at hospitals, medical clinics, pre-schools, elementary schools, courts, and custodial and correctional facilities;
- funding for support services not linked to IQ, but rather to scales of adaptability such as the Vineland Adaptive Behavior Scales and the Scales of Independent Behavior—Revised;
- improvement in statistics and coding systems that will include specific enumeration of FASD and its constituent disorders, their incidence and prevalence, so that resources can be allocated to accommodate effectively the needs of those affected; and
- further research into prevention and treatment.

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