

# ***Fighting for a Future***

**FASD and ‘the system’: adolescents, adults and their families and the state of affairs**

**Proceedings from a two-day Forum: June 19 & 20, 2004; Surrey, British Columbia**

*Prepared by Jan Lutke, Senior FASD Consultant, and Tina Antrobus, FASD Consultant,*

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*Email: [info@fasdconnections.ca](mailto:info@fasdconnections.ca)*

*Web: [www.fasdconnections.ca](http://www.fasdconnections.ca)*

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*To request permission contact:*

*Connections: Serving Adolescents and Adults with FASD*  
[info@fasdconnections.ca](mailto:info@fasdconnections.ca)

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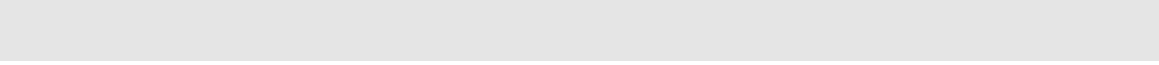
***"The future is not the result of choices among alternative paths offered by the present but a place that is created. Created first in the mind and will, created next in activity. The future is not some place we are going to but one we are creating. The paths are not to be found, but made, and the activity of making them changes both the maker and the destination."***

*John Schaar*

## **Dedication**

**To all the adolescents and adults with FASD who struggle every day to make sense of a world that doesn't make sense; who face more obstacles in one day that we will face in a lifetime and who continue to try long after any other person would have quit.**

**To our last breaths, we will fight for you.**



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# Acknowledgement to Participants

Tina Antrobus  
Vancouver, B.C.  
Bonnie Boucher  
White Rock, B.C.  
Ron Boucher  
White Rock, B.C.  
Maggie Bradshaw  
West Vancouver, B.C.  
Pete Bradshaw,  
West Vancouver, B.C.  
Janet Christie  
Victoria, B.C.  
Rod Densmore  
Salmon Arm, B.C.  
Shannon Densmore  
Salmon Arm, B.C.  
David Duthie  
Delta, B.C.  
Carol Duthie  
Delta, B.C.  
David Fairholm  
Vancouver, B.C.  
Judi Fairholm  
Vancouver, B.C.  
David Gerry  
Victoria, B.C.  
Grace Gerry  
Victoria, B.C.  
Larry Guthrie  
Langley, B.C.  
Monica Guthrie  
Langley, B.C.  
Ken Hokazono  
Delta, B.C.  
Gloria Hokazono  
Delta, B.C.  
Vern Huculak  
Kelowna, BC  
Brenda Huculak  
Kelowna, BC  
Bill Kinsey  
West Vancouver, B.C.  
Karen Kinsey  
West Vancouver, B.C.  
Brenda Knight  
Vancouver, B.C.  
Jennifer Kyffin  
Cobble Hill, B.C.

Jan Lutke  
Surrey, B.C.  
Lloyd Lutke  
Surrey, B.C.  
Steve McGregor  
Abbotsford, B.C.  
Jenelle McMillan  
Clearwater, B.C.  
Claire McManus  
Kelowna, B.C.  
Michael Griffiths  
Kelowna, B.C.  
Lynda Mackie  
North Vancouver, B.C.  
Linda Mitchell  
Surrey, B.C.  
Chris Obansawin  
Surrey, B.C.  
Karen Muxlow  
Surrey, B.C.  
Carrie Prentice  
Mission, B.C.  
Bob Price  
Creston, B.C.  
Diane Price  
Creston, B.C.  
Ken Redman  
Valemount, B.C.  
Genny Redman  
Valemount, B.C.  
Lois Reimer  
Port Coquitlam, B.C.  
Dorothy Reid  
Abbotsford, B.C.  
Rob Richardson  
Kelowna, B.C.  
Pat Richardson  
Kelowna, B.C.  
Michelle Roxborough  
Coquitlam, B.C.  
Diane Schultz  
Surrey, B.C.  
Doug St. Michel  
Victoria, B.C.  
Lori St. Michel  
Victoria, B.C.  
Ed Salahub  
Pitt Meadows, B.C.

Audrey Salahub  
Pitt Meadows, B.C.  
Alan Schmidt  
Mission, B.C.  
Debbie Schmidt  
Mission, B.C.  
Keith Shawcross  
Surrey, B.C.  
Jennifer Shawcross  
Surrey, B.C.  
Michelle Sherbuck  
Surrey, B.C.  
Monica Sivertson  
Kamloops, B.C.  
Stait Sivertson  
Kamloops, B.C.  
Bob Steeves  
Surrey, B.C.  
June Steeves  
Surrey, B.C.  
Terri Smith  
Burnaby, B.C.  
Greg Smith  
Burnaby, B.C.  
Ron Teichrob  
Victoria, B.C.  
Bruce Teichman  
Langley, B.C.  
Marsha Teichman  
Langley, B.C.  
Sue Thompson  
Surrey, B.C.  
Kee Warner  
Burns Lake, B.C.  
Sherri Wood  
Kelowna, B.C.  
Anne Yuen  
Surrey, B.C.  
Sze-Yin Yuen  
Surrey, B.C.  
Bev Zorn  
Prince George, B.C.

# Table of Contents

<b>Executive Summary</b>	<b>7</b>
<b>Broad Recommendations</b>	<b>8</b>
<b>Endnote</b>	<b>9</b>
<b>Preamble</b>	<b>10</b>
<b>Introduction</b>	<b>11</b>
<b>Why is this Important?</b>	<b>13</b>
<b>What does it all mean?</b>	<b>23</b>
<b>What now? Who? Why?</b>	<b>25</b>
<b>Process</b>	<b>27</b>
<b>Strategic Needs Analysis</b>	<b>28</b>
<b>Homelessness</b>	<b>29</b>
<b>Finances</b>	<b>35</b>
<b>Health / Mental Health</b>	<b>45</b>
<b>Education / Programming / Employment</b>	<b>52</b>
<b>Legal / Addictions</b>	<b>58</b>
<b>Family Support</b>	<b>66</b>
<b>Summary</b>	<b>70</b>
<b>Appendix A</b>	<b>71</b>
<b>References</b>	<b>77</b>

# FASD and ‘the system’: adolescents, adults and their families and the state of affairs

## Executive Summary

*“Nothing changes until it does.”*

“There is an urgent need for action to proactively support adolescents and adults with FASD rather than reactively apply ineffective costly measures. The current tragedy in the lives of adults with FASD and their families is a compelling case for action in itself; but the negative social impact on others and social costs related thereto present an overwhelming case for action. Adults with FASD would greatly benefit from coordinated energized action by community, government, business and not-for-profit organizations.” *Larry Guthrie; Director, Risk Management and Financial Services, School District #36, Province of B.C.; parent of an adult with FASD*

To begin the process of addressing this issue, a large, geographically diverse group of birth, foster and adoptive parents, all who are professionally employed in different areas of society, and who have adult children with formally diagnosed FASD, came together in a forum organized by *Connections: Serving Adolescents and Adults with FASD* and funded by *Brewers of Canada*.

During this process, the assembled parents identified what they believed to be the most relevant needs and issues facing adolescents and adults with FASD in today’s society. As well, they explored ideas around service delivery models and services they believe, based on personal and professional experience with this population, would enhance support for individuals with FASD and their families. These two areas are detailed in this report. Lastly, the working group commenced an initial strategic planning process determining what would be needed to effect systemic change to increase not only awareness about these issues and needs, but also to increase, develop and specifically allot service provision and funding to support the needs of persons with FASD and their families. A mechanism was put in place to continue this work and a second two day meeting is planned for September 25 and 26, 2004.

This report has tried to be as representative as possible of the issues and information that were discussed. Many of the same points came up over and over again within different small working sessions. The interconnections cut across all jurisdictions and

all areas, much like knocking over a set of dominos. In the interest of brevity, we have tried to ensure that wherever possible, different information is presented in different places. All of it is critically important.

Broad recommendations derived from the proceedings are as follows. For a complete list of recommendations and steps under each area, please refer to the table of contents and the body of this document.

## Broad Recommendations

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

***intervention point. The development and funding of targeted legal and addiction services that are specific to adolescents and adults with FASD should be considered as a primary risk management tool.***

- 6. The development and funding of consultative processes that have the authority to direct, monitor and evaluate changes specific to the support needs of adolescents and adults with FASD and the particular needs of their families should be considered as a primary broad risk management tool.***

## End Note

Adolescents and adults have unacceptably high level of difficulties that severely impact on the quality of their lives and the lives of those who love and care about them. Their brain damage is significant but rarely understood by those without extensive experience with them. Stability of family placement may mask the extent of their problems during childhood but cannot usually continue to do so upon adolescence. Adulthood presents a crisis point, even for those families who have managed up to that time. Those with FASD do not conform to current standards or guidelines for service eligibility in systems because most are not mentally handicapped, other systems insist the adult (who is adaptively a child) agree to services and still others have expectations for performance within programs the individual with FASD cannot possibly meet. Because they are not eligible for or are not receiving any support services, their disability remains 'hidden' when they come into contact with the legal and addiction systems. These systems treat them as entirely competent adults with the capacity to understand, plan and take responsibility for their actions in the same manner as any other developmentally normal person. They are deemed competent to make decisions with consequences they have no understanding of. The very low level of societal protection and support afforded them by our systems compromises their lives far beyond that caused by their disability. Their adult lives spiral out of control and the cost to them, their families and society at large is incalculable.

It is unacceptable.

The time for change is now.

# FASD and ‘the system’: adolescents, adults and their families and the state of affairs

## Preamble

*“My child’s biggest handicap is society’s insistence on autonomy.”*

How does one describe the multifaceted complexities of FASD in a paragraph? How do you explain, succinctly, the extent of the havoc it can cause in the absence of effective supports? How do you make it clear that mental handicap, the commonly understood definition for developmental disability used in society, is the very *least* of the problems associated with FASD?

Perhaps the best and most accurate description comes out of a book called *Attention, Memory and Executive Function*, edited by G. Reid Lyon, Ph.D. and Norman A. Krasnegor, Ph.D., from the Human Learning and Behavior Branch of the National Institute of Child Health and Human Development in the United States:

“Human learning and behaviour are dependent upon the ability to pay attention to critical features in the environment; retain and retrieve information; and select, deploy, monitor and control cognitive strategies to learn, remember and think. Without these abilities, we could not plan, solve problems or use language. Likewise, being absent of the capacity to attend, remember, organize and structure data within our world, we would be incapable of modifying our behaviour when confronted with new situations. More directly, it would be impossible to generalize what we already know to novel situations and to acquire new concepts and strategies in coping with current, anticipated and forthcoming events if we were not vigilant and attentive, if we could not remember the relevant cues in the environment that led to previous reinforcement, and if we were not strategic in our efforts. Thus attention, memory and executive function (mental control processes) play a central role in thinking, problem solving and other complex symbolic activities involved in oral language, reading, writing, mathematics and social behaviour.”

G. Reid Lyon, in “Attention, Memory and Executive Function”

There is, currently, and in our opinion, no better explanation of why adults with FASD are so disabled.

# Introduction

## *In case you didn't know. . .*

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term now used to describe the group of individuals who have been damaged by prenatal alcohol exposure. Under this umbrella, are found the three main medical diagnoses that describe this birth defect: Fetal Alcohol Syndrome (FAS); Partial Fetal Alcohol Syndrome (PFAS), and Alcohol Related Neurodevelopmental Disorder (ARND). While there are physical differences between diagnoses, ***all*** involve damage to the brain. There is no 'better' diagnosis to have; all can be equally disabling. All are permanent.

FASD is an equal opportunity birth defect, It is found in individuals of ***all*** races, ***all*** ethnic and cultural backgrounds and occurs across ***all*** socio-economic strata. In the largest study of its kind, fully 60% of those diagnosed were Caucasian, 25% were Native American, 7% were African American, 6% were Hispanic, 1% were Asian and 1% were listed as 'other'. (Streissguth et al., 1996).

The vast majority of persons with FASD do not have outward or obvious physical findings that would lead one to think "birth defect"; the primary locus of their birth defects is in the brain. As the child with FASD grows into adulthood, these "primary disabilities" ***do not*** disappear, or even diminish, with age. Their disabilities become ever more obvious, difficult to manage and appear to be exacerbated with the expectations for autonomous, acceptable function within mainstream society that partner with increasing age. Available research also clearly indicates that the "higher functioning" (by IQ measures) individual with FASD is even *more* likely to experience difficulty. (Streissguth et al., 1996).

In the absence of the ***appropriate*** resources, direct services and intensive and time consuming interventions usually required for individuals with FASD, by adulthood many have developed what were first described by Dr. Streissguth, and are now widely acknowledged, as "secondary disabilities". Secondary disabilities are best described as those that were not present at birth (in other words, not caused by the syndrome itself), but result from our failure to recognize and understand the primary disabilities, to intervene early, and to support permanently. These secondary acquired disabilities included such things as early school dropout, lack of employment, substance abuse, mental health disorders, unstable living situations often leading to homelessness, and trouble with the law. The result has been an

enormous influx of adults into the populations of those most marginalized and disenfranchised in our society: the homeless, the incarcerated, the mentally ill, those with addictions. They now overwhelm service systems ill equipped to deal with their complex needs. (*Health Canada FAS/FAE Initiative National Synthesis Report*; Health Canada, 2001)

## Why is this important?

*“Give me a reason to care.”*

Fetal Alcohol Spectrum Disorder (FASD) is a truly unique ‘special need’ requiring very different approaches to support and intervention not compatible with those used with more conventionally understood disabilities. Individuals with FASD have been described, aptly, as the ‘orphan children’ of disability in Canada, poorly understood, poorly served, quickly discarded, and often disposable. They are often the last of the least; the truly disenfranchised. In the 30 years since FASD was first described, research has not kept pace with the burgeoning numbers of affected persons. The lack of professional understanding of the extent to which this disability is different than other handicaps and requires different approaches, has meant we are now in the urgent position of attempting to play ‘catch-up’ in a major way.

The accepted rate of FAS, which is by far the *least* common of the birth defects caused by drinking in pregnancy, is 1.9/1000 for *full* FAS in North America (combination of full FAS, PFAS and ARND) the accepted rate is a *minimum* of 1/100 in North America, or 1% of population. (May and Gossage, 2001 and Sampson et al., 1997).

Conservatively, the minimum number of individuals with FASD in Canada is 1% of population, or about 317,146 (Cdn population October 2003 of 31,714,637) *Stats Canada Data*; persons, in B.C., would be 41,586 (BC population October 2003 of 4,158,649). For the population ages 15 and older, there are over 25,848,000 persons in Canada, of whom about 258,480 can be expected to have FASD. There are just over 2,879,600 people between 15 and 64 in B.C, of who 28,796 can be expected to have FASD. This is conservatively the ***lowest*** number of individuals with FASD that can be expected to exist in Canada and B.C. This is not a high-risk statistic; merely the reality of the numbers for the population in general. While there is no definitive research on actual numbers of adults with FASD found in specific sub-populations, they appear to become concentrated in certain areas of society where rates can be expected to be much higher than 1% (i.e.: homeless, incarcerated).

In some communities which are considered to be high risk due to alcohol abuse, and in which all children between 0 and 19 have been examined and assessed, rates are 1/5. (Robinson, Conry, and Conry, 1988; and Williams, Obaido and McGee, 1999).

There is no research on children in foster care but of the 800 to 1,000 available for adoption in B.C., at least 80% have a history of prenatal alcohol exposure. (Ministry of Children and Families Development, Adoption Education Programs Information to Prospective Adoptive Parents, Province of B.C.). Rates can be expected to be very high in adopted persons (and is likely a factor in the number of adoptions that break down in adolescence). International adoptions from Russia and the Eastern Bloc countries show approximately 15% of children with full FAS (the PFAS and ARND cannot be diagnosed because of an absence of documented history of maternal alcohol use in pregnancy; only full FAS can be diagnosed in the absence of this history). (Aronson, Jane M.D. (1997); *Prevalence of FAS and FAE in Pre-Adoptive Evaluations of Children in Russian Orphanages*). Current research and partner studies between Russia and San Diego State University in the USA show rates even higher. Dr. Ron Federrici, an adoption physician estimates that of the children he has seen in some Russian orphanages, fully 38% are FAS (*Peggy Oba, personal communication*). Highest rates in the world are in South Africa where the rate for full FAS is 40.5 to 46.4 per 1,000 - PFAS and ARND are not even considered in this statistic. (*Fetal Alcohol Syndrome – the South African Nightmare (2003)*; [Journal of FAS International](#)).

While there is currently no way to tell which women are most likely to give birth to an alcohol affected child, it is known that once a woman has given birth to such a child, the likelihood that each succeeding pregnancy will be affected increases dramatically. Rates of FASD in sibling groups range from a low of 170 per 1,000 (17%) for older sibs and a high of 771 per 1,000 (77%) for younger siblings once a child has been diagnosed in a sibling group. The implications for families should be obvious. Many will be raising more than one affected individual.

The average IQ in FASD is between 75 and 85, with the full range in FASD being between 20 and 140+ (*intellectual* mental handicap is IQ <70) but ***almost all*** individuals with FASD have an adaptive quotient (AQ) <70. AQ measure one's ability to function day to day *without* supports in the areas of communication, socialization, daily living skills (personal and community), time management, employment, critical thinking, judgment, etc.). Adaptive functioning can be measured and scored, using test instruments in the same way as IQ. AQ <70 is considered *adaptive* mental handicap.

In almost all other individuals, whether handicapped by some other mechanism or not, IQ and AQ are within a couple of points of each other, compliment each other and work together to create a whole, allowing for independent functioning. One of only a couple of exceptions to this is FASD. The gap between IQ and AQ is huge in

FASD, anywhere from 10 to 60 points. The average AQ in one study is about 53, clearly in the moderately mentally handicapped range, defined as scores below 55. (Russell, 2003). Additionally, Streissguth et al. (1996) report the average IQ in 178 clients with FAS was 79 with an average AQ of 61; while 295 clients with FAE (now PFAS/ARND) had an average IQ of 90 and an average AQ of 67. Adults with FASD are handicapped to such a degree that they are unable to manage the mechanics of daily life or access services or supports on their own; the process is too difficult for them.

Appropriate and effective schooling that meets the educational and vocational needs of adolescents and adults with FASD does not currently exist unless they meet eligibility requirements for mental handicap, severe behaviour disorder or occasionally, severe learning disability. **As a general rule, there is no funding category into which they fit.** Even when eligibility for services has been allowed, existing programs and services seem to be a poor fit and unable to meet what are quite different needs. As a result, most find themselves in inadequate settings which only serve to exacerbate their difficulties with learning, peers and teachers to the point where their schooling ends well short of completion. Research shows that overall, 60% of individuals with FASD over the age of 12 have been suspended, expelled or dropped out. According to Streissguth et al. (1996), the following rate of disrupted schooling is noted in those with FASD over the age of 12:

Sample	Disrupted Schooling (Percentage)
• Females with PFAS/ARND (ages 21 – 51)	76%
• Males with PFAS/ARND (ages 12 – 20)	76%
• Males with PFAS/ARND (ages 21 – 51)	70%
• Males with FAS (ages 12 – 20)	70%
• Females with FAS (ages 21 – 51)	52%
• Females with PFAS/ARND (ages 12 – 20)	50%
• Males with FAS (ages 21 – 51)	43%
• Females with FAS (ages 12 – 20)	30%

Of this group of adolescents and adults, over 70% had repeated problems with attention, 60% had repeatedly incomplete homework, almost 50% had failed a grade, and almost 40% had *repeatedly* failed classes.

Behaviour problems were cited at very high rates as follows:

▪ Difficulty getting along with peers:	60% (ages 12 – 20) 54% (ages 21-51)
• Disruptive in class:	57% (ages 12 – 20) 44% (ages 21-51)
• Disobeying school rules:	49% (ages 12-20) 34% (ages 21-51)
• Talking back to teachers:	45% (ages 12-20) 33% (ages 21-51)
• Fighting:	38% (ages 12-20) 31% (ages 21-51)
• Truancy:	37% (ages 12-20) 38% (ages 21-51)

Forty percent of these individuals had been in special education classes of some sort – a service that has been clearly ineffective for them, given the very high rates of difficulty and disrupted schooling.

*Sole* qualification in B.C. for eligibility for even minimal adult support services from Community Living Services (CLS) of the Ministry of Children and Families (MCFD) is *IQ alone* below 70. Adaptive function is not factored in *unless* the individual has an IQ <70, at which time it is clearly recognized that the individual will need help with all areas of daily living. (CLS of MCFD is the only branch of social services where even the most minimal of supports can be obtained, and is not able to adequately serve the numbers of its current clients). At no time are the serious executive functioning deficits found in those with FASD who are considered to be 'high functioning' factored in. (Kerns et al.,1997).

While there is a dearth of hard research on adults with FASD over time, there is a magnitude of anecdotal information from multiple sources, all reporting the same thing. This lack of eligibility and lack of support service provision is directly tied to poor outcomes in FASD, and undoubtedly related to homelessness in this group of adults. Individuals with FASD are seriously disabled by their prenatal alcohol exposure and resultant brain damage and unable to maintain stable housing, live independently, maintain employment and healthy lifestyles unsupported.

Attention Deficit Hyperactive Disorder (ADHD) is also a commonly seen co-morbid disorder with FASD – different studies estimate between 60-85% of affected individuals. The ADHD is *different* from typical ADHD and is likely a particular

clinical subtype of ADHD that is caused by prenatal alcohol exposure, and can be seen with FASD or without FASD. As such, it frequently does not respond as well to medication and occasionally, medication may actually make it worse. Individuals with FASD related attention deficit have difficulty with “encode” (integration of information and generalization) and “shift” (perseveration; changing approaches or tasks) components of attention, whereas those with typical ADHD have trouble focusing and sustaining attention. ***The distinction is critical for effective intervention.*** (O’Malley and Nanson, 2001; and Coles, 2001). From an intervention standpoint it may also be critical to consider how many adults with a childhood diagnosis of ADHD are, in fact, persons with undiagnosed FASD, and not ADHD at all. Misdiagnosis is common for a variety of reasons, including bias and the unwillingness of physicians to ‘label’ a child as alcohol affected. Given the connection between early alcohol use, alcoholism (leading eventually to homelessness) and a ‘diagnosis’ of ADHD, this must be considered (Smith, Molina and Pelham, 2002).

Research also indicates that the mental health disorders so prevalent with FASD do not begin in adulthood, but rather start in childhood (O’Connor et al., 2002; O’Connor and Kasari, 2000; Steinhausen, Willms and Spohr, 1993; and Steinhausen, Nestler and Spohr, 1982).

Mental health problems are overwhelmingly prevalent co-morbid diagnoses in adults with FASD, and due to the nature of their brain damage, standard mental health treatment has not been effective. Overall, 94% of affected individuals with a diagnosis of FASD have at least one mental health diagnosis in adulthood. According to Streissguth et al. (1996), the following is noted in adults:

Mental Health Diagnosis	Percentage of Sample
• Depression	52%
• Continuing ADHD problems	Over 40%
• Suicide threats	43%
• Panic attacks	33%
• Psychosis (hearing voices / seeing visions)	29%
• Suicide attempts	23%

- 100% of alcohol affected men (PFAS/ARND) have at least one mental health diagnosis
- 88% of men with full FAS have at least one of the above 100% of women with FASD have at least one of the above
- IQ over 85 is **not** a protective factor, and rates are highest in this group (although only slightly)

Research on adults with FASD has increasingly demonstrated over the years that substantial mental illness accompanies this syndrome (Famey, et al.,1998; Lohr and Bracha, 1989; Lohr and Bracha, 1978; Cadoret and Riggins-Caspers, 2000; and Carmichael-Olson, Morse and Huffine, 1998).

Research also shows that adults with FASD have high rates of substance use disorders. Streissguth et al. (1996) found that 30% of adult males over 21 with FAS had substance use disorders and 54% of adult males over 21 with PFAS or ARND had substance use disorders. The rates were even higher in women with FASD. Among clients with alcohol and drug abuse problems, alcohol abuse preceded drug abuse by an average of two years. Similar rates were also found in B.C. (Clark, 2003). Parents and professionals working with adults often report an ‘all or nothing’ problem with substance use, and that *any* use leads quickly to serious addiction. To date, and most likely due to the nature of their brain damage, conventional treatment programs have not been effective with this population. Substance use leads very quickly to the loss of whatever community supports, housing placements and employment options that may have been provided and leads individuals into criminal activity.

Overall, according to the Secondary Disability Study, 35% of those aged 12 and over with FASD have problems with drugs and alcohol:

Sample	Drug & Alcohol Problems (Percentage)
Females with PFAS/ARND (aged 21 – 51)	70%
Males with PFAS/ARND (aged 21 – 51)	54%
Females with PFAS/ARND (aged 12 – 20)	38%
Females with FAS (aged 21 – 51)	37%
Males with FAS (aged 12 – 20)	32%
Males with FAS (aged 21 – 51)	30%
Males with PFAS/ARND (aged 12 – 20)	30%
Females with FAS (aged 12 – 20)	4%

- 23% have been in treatment – and 70% of these had their first alcohol treatment before the age of 21
- alcohol abuse precedes drug problems by 2 years
- 65% of those over 12 who abused alcohol went on to abuse street drugs

Trouble with the law figures range from about 24% to 60%+, depending on the studies, which are limited in number. For those 21 and over, Streissguth et al. (1996), found that:

- rate of crime for adult males with FAS – 57%; adult females with FAS – 45%;

- adult males with PFAS/ARND – 77%; adult females with PFAS/ARND – 65%
- crimes committed by adults with FASD:

Crime	Percentage of Sample (age 21+)
Against persons (everything from shoplifting to murder)	42%
Possession / selling drugs	23%
Vehicular	20%
Property offences	17%
Sexual assault	14%
Status offence	9%
Other	7%

For those age 12 – 20, Streissguth et al. (1996) found the following:

- rate of crime for males (age 12-20) with FAS was 59%; females with FAS was 40%
- rate of crime for males (age 12-20) with PFAS/ARND was 71%; females with PFAS/ARND was 57%
- crimes committed by males and females (age 12-20) were:

Crime	Percentage of Sample (age 12 – 20)
Against persons (everything from shoplifting to murder)	47%
Possession / selling drugs	18%
Vehicular	5%
Property offences	28%
Sexual assault	14%
Status offence	11%
Other	6%

- For youth and adults with FAS - 31% committed shoplifting/theft as their first offense, and for those with PFAS/ARND 39% committed shoplifting/theft as their first offense.
- Only 5-6% of individuals with FASD committed assault as their first offense; and only about 2-5% committed child molestation as their first offense.
- Only 5% of people with FAS experience their first trouble with the law after the age of 20.

Streissguth et al. (1996) also found that 80% of those in trouble with the law also had disrupted schooling; and 69% of those who commit crimes against persons also have problems with alcohol and/or drugs. ***Lack of alcohol and/or drug problems cuts the rate of trouble with the law by almost half.***

To date, legal decisions have assumed, erroneously, that low IQ or facial features must be present for disability, which results in judicial decisions with serious consequences for the individual (*Fetal Alcohol Syndrome/Fetal Alcohol Effects Legal Resource Center, Fetal Alcohol and Drug Unit, University of Washington School of Medicine and University of Washington School of Law, July 2003*). These adults are among those most likely to become homeless upon release from prison, the least likely to be able to apply for social assistance and very likely to have lost family support.

No mechanism exists to track rates of FASD in Canadian jails. The minimum number, based on the 1/100 or 1% accepted statistical rate would be 1,539 inmates with FASD in the combined provincial and federal systems (148,797 provincial and 20,372 federal inmates = 1,354 provincial FASD and 185 federal FASD) (Burd, Selfridge, Klug, Juelson 2003; Burd, Martsof and Juelson, 2004). These numbers assume that only 1 in 100 of those in jail has FASD, when limited studies indicate up to 60% (or 60 out of 100 people with FASD) are in trouble with the law – which would mean that the numbers incarcerated with FASD should be much higher than 1 in 100 in the general inmate population. People with FASD are **concentrated** in jails – use of general population data may not be reflective. *The corrections system is the only system that cannot deny ‘eligibility’ – in the absence of supports (housing, employment programs, counseling, support workers, etc.) it is the default social safety net for adults with FASD.*

For those adults with FASD over the age of 21, fully 80% are unable to live independently (FAS – men 80%; women 85%; PFAS/ARND - men 100%; women 70%). *This finding is independent of IQ scores* (Streissguth et al., 1996). Streissguth et al. (1996) found that adults with FASD were unable to:

Activities of Daily Living	Percentage of Sample Having Difficulty
▪ Manage money	83%
▪ Poor judgment	82%
▪ Make decisions	78%
▪ Poor organization skills	77%
▪ Obtain social services	70%
▪ Get medical care	67%
▪ Handle interpersonal relationships	57%
▪ Grocery shop	52%
▪ Cook meals	49%
▪ Structure leisure activities	48%
▪ Stay out of trouble	48%
▪ Handle hygiene	37%
▪ Use public transportation	24%

The urgent need for safe, stable housing that can provide support for financial management, chores, nutrition, shopping, hygiene, health care, addiction treatment and all the other areas that make up daily living has been identified consistently by researchers (Clark, 2003; and Rutman, LaBerge and Wheway, 2002) and is referenced throughout these documents. Adults with FASD have consistently proven to be unable to live independently. They have complex, multi-faceted needs that cannot be addressed in isolation or through existing resources, programs and intervention models.

Similarly, for an adult over 21, research has documented that fully 80% are unable to obtain or retain a job, *regardless of IQ*: FAS – men 72%; women 96%; PFAS/ARND – men 76%, women 65%. Streissguth et al. (1996), report that problems experienced in employment include the following:

<b>Employment Related Problem Areas:</b>	<b>Percentage of Sample Had Difficulty</b>
▪ Easily frustrated	65%
▪ Poor task comprehension	57%
▪ Poor judgment	55%
▪ Social problems	54%
▪ Fired	50%
▪ Unreliable	42%
▪ Anger management	42%
▪ Problems with supervisor	40%
▪ Lying	33%
▪ Lose jobs without understanding why	30%

Employment is not a current reality for most adults with FASD because of the lack of services and supports necessary to make it happen. For those who might potentially be able to manage some work, residential supports must be in place *first* or the possibility is nothing more than an idea that will never be tested.

As with the general population, individuals with FASD also become parents. Their disabilities, however, can make adequate parenting very difficult in the absence of sustained, long-term supports. Such supports are almost always available only through family, and family become tired and burned out. In the absence of such support, or on the loss of it, many adults with FASD lose custody of their children to child protection services. In order to prevent the permanent loss of grandchildren, families may then have to step in and commit to raising one or more grandchildren, a task most are no longer able to afford – physically, financially and emotionally - the reasons why support to the adult child ended in the first place.

Research on adults with FASD as parents is very limited; what does exist, states

- only 30% were diagnosed before they became parents
- 11% diagnosed around the time they became parents
- 59% diagnosed after they became parents
- Child apprehension rate from mothers was 36%
- Child abandonment rate by fathers was 45%
- 40% of the mothers drank in their pregnancies
- 17% of those children diagnosed FAS/PFAS
- Additional 13% suspected of being FASD

*Anecdotal reporting states that these may well be conservative figures in terms of child apprehension and technical abandonment*

# What Does It All Mean?

***“You can pay now or you can pay NOW. There is no such thing as ‘pay later’.”***

The economic costs of FASD are enormous. Estimates for cost range from a low of 1.5 million dollars to a high of five million dollars US (2.9 million ++ Cdn) per individual over the course of a lifetime. These figures do not include the costs of incarceration, lost productivity, burden on families and poor quality of life (*FASD Fact Sheet, FASD Center for Excellence, Substance Abuse and Mental Health Services Administration, US Department of Health, 2003*). Only minimal costs for residential care are included and only for those with mental handicaps up to the age of 21.

A 2004 updated cost estimate for FAS *alone* puts the dollar figure at two million per individual. While adding in some costs for residential care to age 65 for mentally handicapped individuals, most associated costs are still not included, and none of the costs associated with PFAS and ARND. In a study published in 2001, the unreimbursed cost to families in North Dakota for FASD was more than \$17,000 US per child per year (Burd, Klug, Hoesel, Moum, 2001). Current adjusted cost of FAS *alone* in the United States is estimated to be \$3.6 billion dollars a year. (*Cost of Fetal Alcohol Spectrum Disorders; American Journal of Medical Genetics Part C (Seminars in Medical Genetics); Volume 127C; 2004*)

“There is an urgent need for action to proactively support adults with FASD rather than reactively apply ineffective costly measures. The current tragedy in the lives of adults with FASD and their families is a compelling case for action in itself; but the negative social impact on others and social costs related thereto present an overwhelming case for action. Adults with FASD would greatly benefit from coordinated energized action by community, government, business and not-for-profit organizations.” *Larry Guthrie, parent, Director, Risk Management and Financial Services, School District #36, Province of B.C.*

The lack of resources and services to address the specific needs of older adolescents and adults with Fetal Alcohol Spectrum Disorder (FASD) is a looming social tragedy of epidemic proportions, unprecedented in recent Canadian history. With the lifetime costs for one individual with FASD (exclusive of the legal system) now estimated at over two million dollars US, the financial costs of continuing to

ignore this population should be of equal concern to all systems. There is an *urgent*, indeed *critical*, need to increase the visibility and understanding of this permanent, lifelong disability, and its consequences for the individual, family and society.

# What Now? Who? Why?

*“At the end of the day, everyone else gets to go home.”*

To begin the process of addressing this issue, a large, geographically diverse group of birth and adoptive parents, all who are professionally employed in different areas of their community and who have adult children with formally diagnosed FASD, came together in a forum organized by *Connections: Serving Adolescents and Adults with FASD* and funded by *Brewers of Canada*.

This group of parents was invited to participate in this process based on a combination of considerations: post secondary education or training, professional background, personal experience, experience working with adults with FASD, family makeup and adequate mental health. Collectively, this group was aware of almost every resource and service currently available in B.C. for those with ‘special needs’ and had experience with all of them. They were highly cognizant of the differences between all other disabilities and FASD, and the pitfalls therein. Their children, with two exceptions, ranged from very late adolescence to mid thirties in age, and covered the spectrum of disability. IQs represented the full range as reported in the research – from a low of 47 to a high of 120. Some had been diagnosed in early childhood, some in adolescence and some not until adulthood. Some were functioning within acceptable limits and some were on the streets or in jail. About 30% of their adult children were also parents. Many struggled with substance use disorders. All their children have had many difficulties in life to overcome and **all** require supports in adulthood for function. **None** are completely independent.

This hand-picked group consisted of adoptive and birth parents who are also professionals in the community. Some began with significant personal and financial resources at their disposal. Some began with only a little, and some began with nothing at all. Over the years, irrespective of differences, each has had experiences all too similar while raising a child with FASD. Regardless of where the journey began, each family in the room arrived at the same fork of recognition in the road. Once the resources have been exhausted, and they always will be because they are finite, there is no safety net for either the family or the affected adult. Thus the experiences of all families (professional, white-collar, blue-collar, impoverished or recovering from substance use) raising someone with FASD are similar in this respect. The issue is not whether or not they will run out of resources, but only **when** they will run out of resources. Social standing, personal resources, personal health,

and money do not protect in the long term. They only delay the inevitable. The family, however constructed, is the 'mini-institution': when it can no longer meet the needs of the adult with FASD, everything fails.

FASD is the 'great leveler'. In this simple but overwhelming fact lie the commonality of experience, and the ability to work together for a purpose greater than one's differences.

## Process:

*“Is anyone listening – we are out of time.”*

This two day forum was held June 19 and 20, 2004, in the Lower Mainland area of B.C. Participants were charged with determining which specific issues were in most urgent need of address and determining the most effective and organized way to begin the long-term process of effecting positive change.

### **One parent’s vision:**

“A Canada where adults with FASD can contribute positively within their communities and be supported to lead fulfilling, productive lives *within the limits of their disability*”.

During this process, the assembled parents determined what they believed to be the most relevant needs and issues facing adolescents and adults with FASD in today’s society. As well, they explored ideas around service delivery models and services they believe, based on personal and professional experience with this population, would enhance support for individuals with FASD and their families. Lastly, the working group commenced an initial strategic planning process determining what would be needed to effect systemic change to increase not only awareness about these issues and needs, but also to increase, develop and specifically allot service provision and funding to support the needs of persons with FASD and their families. A mechanism was put in place to continue this work and a second two day meeting is planned for September 2004.

The following is a summary of the key issues presented on the first day of this forum.

# Strategic Needs Analysis:

*“How do you eat an elephant? One bite at a time.”*

GOAL: to determine, define and refine multiple issues in order to group collectively under five or six topic headings, without relevance to priority, in order to provide a framework for the ‘next steps’ development of a strategic plan of action

DISCUSSION: a concentrated, facilitated discussion was held in the group as a whole across a very wide range of concerns. Consensus was reached that issues could best be synthesized under the following headings:

- Housing and Homelessness
- Finances
- Health and Mental Health
- Education, Programming and Employment
- Legal and Addictions
- Family Support

The large group then separated into smaller working groups represented by the six themes above. Each group was tasked with elaborating on and defining these six key areas of issues. Without limiting the discussions, they were asked to broadly consider (1) what needs are specific to the issue; (2) what gaps exist in service to address this issue and (3) recommendations for action. The following are the results from these facilitated small working groups discussions.

# Housing / Homelessness

*“The absence of a home is the absence of everything.”*

This group began by posing two questions “what does housing mean?”, and “what is independence related to?” It determined that housing meant more than four walls and a roof; a place to live. Rather, a successful housing situation should be a safe home; a place to belong and a place to be; a place in which all other activities of life occur in, out of, or around. It is intimately related to the concepts of being ‘independent’ and ‘responsible’, and largely inseparable from the ability to manage activities of daily living (ie: household chores, paying bills, appropriate social behavior and interactions with others, obtaining and maintaining financial stability). For the non-alcohol impacted adult it is an expected function and rite of passage to which very little thought is given. The ability to just ‘do’ is automatic.

For the adult with FASD, housing is the foundation upon which everything else rests. *The absence of housing is the absence of everything.* Housing – especially housing that is a *home* - means being part of a community, socializing, buying groceries, accessing transportation and community services, forming relationships and friendships, developing history, and having a safe place to go and be. These are crucial components of being able to take part in society in a meaningful way, and will be essential for those growing up with FASD today who will become tomorrow’s adults. This housing – these *homes* - must be available, affordable and accessible regardless of IQ. A comprehensive range of supported housing services and options will be required and should be designed to meet the individual needs of persons with FAS. *Systems must not assume that all persons with FASD are the same or require the same sorts of approaches and levels of support.* One size does not fit all.

There was wide ranging discussion about what ‘independence’ meant, and a lengthy list of necessary individual functions was drawn up. Consensus was that independence could best be described as the ‘ability to come and go as you please, as needed, safely, within the law, without help and without problems’. How do systems and people determine an individual’s ability to do this? In the absence of a mental handicap, there is no set way, they just do it, and usually it is based on ‘snapshot’ appearances and language use which can be particularly deceptive with FASD. Discussion centered on the complexities of such inaccurate functional expectations and whether or not these were ever realistic for late adolescents and adults with FASD, irrespective measured IQ. Given research, the extent of the

adaptive handicaps seen in this population and the collective practical, professional and personal experience, it is the position of this group that adolescents and adults with FASD will likely always need varying degrees of help with daily living, regardless of living situation. They will need someone or a system in place over time to ensure that the activities of daily living are both manageable and managed. It was noted that “people gravitate to whatever works for them, good or bad – that’s the normal thing to do. With FASD, every little piece has to be put together for them.” Without this, the expectations for ‘independence’ are too high and the result is almost always practical or actual homelessness once the family is no longer able to provide the extensive financial and practical supports that are needed to allow for adult function. At some point, all people have to leave home, and systems must come to terms with the new and emerging demographic of FASD.

The importance of individual living programs was emphasized within an environment best able to provide a very high degree of safety to residents, as well as 24 hour per day, 7 day per week supervision availability. Great emphasis was placed on the need for, and provision of ‘external structures’ to increase the ability of persons with FASD to function acceptably in the housing environment, however constructed. It was strongly recommended that a zero-tolerance policy in housing be viewed as not only unrealistic, but highly detrimental to the success of maintaining housing placements for older adolescents and adults with FASD experiencing the highest level of secondary disabilities and most difficulty with behaviours.

Housing that provides various kinds of on-site staff support, peer mentoring, outreach workers, volunteers, ‘relationship referees’ and leisure buddies was seen as critical for efficacy. Built in programs attached to different kinds of housing may provide for skill development and should be geared to the unique needs of each resident. Given the very wide range in cognitive functioning seen with FASD, an equally wide range of programming will be required to address this. Programs should include assistance with all activities of daily living as housing is the base in and from which such activities occur. Leisure and recreation programs are also vital program components to decrease social isolation, boredom and the effects of negative peer pressure among adolescents and adults with FASD. They should be viewed as integral components, and not as add-ons to be discarded when funding is tight.

At the present time, there are no long-term supported or transitional housing services available anywhere in B.C. specifically designed to meet the complex needs of adults with FASD who either cannot, or do not live at home. Their need is acute. Currently, if they are served at all, they are provided for within existing emergency shelters on a very temporary basis. The most dysfunctional are often among the most difficult clients, combining not only brain damage, but addictions and mental health issues.

Very occasionally, they may find housing within low-cost housing units prepared to accept them, but the absence of continuous on-site support and supervision makes this a most unworkable situation leading to eviction even from resources designed for those with special needs. These adults have the deceptive *appearance* of capability, but no actual, underlying ability.

The adaptive handicap that is the hallmark of FASD means the impacted adult has no ability to function or handle the ‘nuts and bolts’ that make up daily life, problem solve, handle changes, think critically, use judgment or modify behaviour without skilled help. More importantly, the impact of this disability is such that most of those with it have little or no insight into their disability or awareness of the extent to which they require support. They are simply bewildered, frustrated and hostile when things go wrong as they are want to do – consistently, persistently and with ever increasingly more serious consequences for both the individual himself and society. They have significantly impaired ability to learn from consequences and such poor memory that learning is not well retained, if retained at all. At risk and practical homelessness is the *norm* for adults with FASD, even for those who still have some degree of community or family support, and absolute homelessness is often the reality in the absence of such supports. Increasingly, over time, those adults who were “at risk” become the absolute homeless and likely make up a sizeable portion of those adults on the streets who are completely without even the possibility of stable housing at the present time. It is this absolute “*knowing* what will happen” that places families in such untenable positions.

There is limited research on adults with FASD and the ability to live independently. What does exist and an abundance of anecdotal evidence is consistently clear that over 80% are unable to function in the absence of supports well enough to live on their own or maintain employment. This group of adult clients rarely qualifies for social service supports via the Community Living Service system even though they have a medical diagnosis of a syndrome known to severely limit function. It is unarguably true that a significant percentage of them will end up homeless and/or incarcerated due to the extent of their adaptive deficits, especially once they no longer live in the family home. Research has also found that the rates of difficulty with independent living are greatest in the group of so-called ‘high functioning’ adults with FASD – those with the highest IQ scores (average of 90). This group is also over-represented in those with mental health issues and substance abuse disorders. The result is a very hard-to-house group of individuals in the best of circumstances.

However, the consensus of opinion over many years of those living and working directly with affected adults who are not able to maintain housing is that a goodly

portion of them *could* be housed successfully, *if* behaviour can be stabilized and *if* long term supports are made available as and when they are needed, and *if* a crisis response system is in place.

Many adults with FASD are difficult to house, no question about it. They do not follow rules because they do not understand them or that they are unaware that those rules are meant for them, too. They cannot remember them, they cannot apply them and they cannot be expected to learn from them and change behaviour as a result of them. This is the consequence of brain damage, not deliberate, thought-out or planned behaviour. Any proposed resource would have to work around these deficits, and have a different set of expectations – that: such behaviour is ‘normal’ for FASD; such things are bound to happen and are not a reason for exclusion from the residence; a very high level of on-going support is required for appropriate and positive function; such support will need to be in place for life; and must acknowledge and accept that change is a very slow process.

For the most part adults with FASD who are not able or are unwilling to live in a family home ‘couch-surf’ - sleeping wherever they can find a bed for the night until they run out of places to go. Some of them sleep outdoors. Regardless of where they stay, their needs are poorly understood and they require a much greater intensity, consistency and persistency of support and supervision than is possible to provide without the development of a specific housing service for those with FASD.

***It is anticipated, based on what is currently known about those adults with FASD who are functioning and the precise nature and types of supports they receive from families and support persons, that such a model could: reduce the high rates of criminal involvement to get basic needs met; facilitate the development of skills on an FASD developmental timeline; reduce the high rates of untreated mental illness in this population; improve physical health and nutrition; reduce addiction; provide positive social support networks; develop pre-employment readiness skills and encourage re-connection with supportive family members.***

Adolescents and adults with *diagnosed* FASD and *suspected* FASD are overwhelmingly over-represented in the population of persons with addiction and mental health issues, those who are homeless, and in particular, those who are perpetually at risk of becoming homeless. They are among the most difficult to maintain in stable housing.

Any proposed solution must seek to begin the process of addressing residential housing and supports from a systematic, planned, multi-pronged approach which will provide long-term (*not* short-term) supportive housing, stabilization of FASD behaviours leading or related to homelessness, transitional and outreach services for those who do not require intensive supports, and crisis services to prevent homelessness. It must use recommended FASD intervention protocols based on what is currently known about this group of high risk, high need adults, and attempt to develop 'best practice' approaches based on experience gained. Due to the large numbers of people in society who have FASD, the need is significant for this type of housing service.

### **Action for Change:**

There is a critical need to develop, co-ordinate and fund a system of housing care for adolescents and adults with FASD, with eligibility based on either diagnosis **or** adaptive deficits, which will:

- Investigate, design, develop, create, locate and manage a full range of permanent, flexible housing support alternatives to incorporate a 'good fit' for individuals with FASD.
- Find and fund a broad range of appropriate and flexible supported housing services on a case-by-case basis for those impacted with FASD to meet a wide spectrum of need, and provide a continuum of education & support for landlords and caregivers.
- Subsidize rents for those who are able to manage on their own with less help but who are not able to live successfully with a roommate in order to provide adequate standard of living
- Design and implement Individualized Living Programs (ILPs)
- Case manage *very* specifically and *very* flexibly to each individual
- Discard the 'zero tolerance' concept
- Understand, support and fund the concept of 'on-going temporary crisis management'
- In all cases, recognize that the inability to manage money combined with a poverty income will require financial trusteeship to prevent eviction
- In all cases, place the emphasis on safety of the individual
- Provide ongoing evaluation to develop 'best practices' models for sustainable housing supports for adolescents and adults with FASD

***Safe, stable, secure, supported, structured, supervised subsidized housing (7S Model) should be considered the primary key to broad risk management for adults with FASD. The absence of housing is the absence of everything.***

# Finances

*“Money, money, everywhere, but not a cent to spare.”*

This session began by asking the questions “what do we know about the costs to society?” and “what do we know about costs to the family system?”

There are only a handful of studies with respect to the costs of FASD, and none are inclusive of all costs. None look at quality of life and none factor in indirect costs to the family. Service costs are based on those provided to individuals with mental handicaps and do not include anything for the majority who are not. Much of the research estimates costs for FAS alone, and does not include the much larger costs for PFAS and ARND. All studies are American. The most current of these studies now estimates costs over the lifetime (to age 65) for one person with FASD to be \$2,000,000 US or, translated into August 2004 Canadian dollars, about \$2,640,000.

None of these studies includes the costs of the criminal legal system, possibly because costs are much lower due to the differences in their system. In Canada, those costs are very high, as we use a rehabilitative system of justice rather than a strictly punitive one. A provincial jail cell in B.C. costs in the order of \$150-250 per day (between \$4,500 and \$7,500 per month or \$54,750 and \$91,250 per year). A federal jail cell costs in the order of \$100,000 per year and up, depending on classification. Juvenile facilities are even more costly, running at the rate of about \$300 per day or \$9,000 per month and \$108,000 per year. These costs are not factored into costs of FASD to society. Costs for crime itself, insurance, policing, court time and staff costs, cost of legal aid or lawyers, judges, probation and parole services, victim compensation, etc. are also not factored in. An individual with FASD who has become embroiled within the legal system and is incarcerated may spend much of his adult life in jail since we have, at the present time, no alternatives to support him elsewhere. With increasing length of sentence for each crime, it is logical to estimate that such an individual would very quickly cost society over \$1,000,000 in jail cell alone, and could potentially reach \$2,000,000 for jail time by his 45<sup>th</sup> birthday. The omission of this data would seem to be a significant oversight.

The costs of foster care can be considerable. B.C. uses a leveled system of care, in which caregivers are ‘paid’ according to a set of demonstrated knowledge skills and abilities, without regard to the child who may be placed there. Rates of compensation, designed to cover all costs of the child and, in some cases, a small

'fee' for the caregiver, range from a low of about \$750 per month for 'regular care' to a high of about \$2,700 per month for 'Level 3 care'. In some instances costs are much more than this for very difficult adolescents who may be maintained in highly specialized and staffed resources. These costs can range upwards of \$10,000 per month per child. Many children with FASD will be found in the leveled system homes, and most of those residing in regular rate homes are there only because budget constraints do not allow for placement elsewhere. Their behaviour usually escalates in the absence of skilled parenting and they 'cascade up' the levels of care, becoming ever more expensive to maintain in increasingly costly resources.

Regardless, foster care costs, exclusive of anything not paid directly to the caregiver, amount to between \$9,000 and \$32,400 per year per child. Should a child remain in the foster system for 10 years (which many do) this cost alone can reach \$324,000. This cost does not include social work time, court time, treatment costs, supervision for visits, or the multitude of other costs associated with foster care. If the child is returned to the biological family, parents may well be on social assistance. Supports such as daycare services, respite care and family counseling may well be provided. Should the child be placed for adoption, it is likely that limited financial assistance will now be provided to the family and/or that specific services will be paid for. These are all cost items. Basic financial maintenance, respite care, treatment with a competent therapist, orthodontia, extra supervision costs, etc., can add up to very substantial amounts of money. One parent will most likely be required to leave employment to provide full-time care and supervision to the child at costs in the neighbourhood of \$30,000 or more per year in lost income to the new family. This is not a temporary employment absence as with the birth of a child, but one which will become increasingly necessary as the child grows up, and often becomes acute in adolescence and adulthood.

What about the cost to society of an adult with FASD who is now a parent? Typically, systems remove children from these parents after many costly failed attempts to provide short-sighted, temporary stop-gap service measures to "fix" the problem. All existing supports fail to accommodate brain damage and have expectations for function that cannot be met without ongoing in-home or on-sight services. If family does not want to lose grandchildren, or see the adult child lose a child, they must step in and assume legal custody with all of the unsupported attendant costs – financial, legal, social, emotional, psychological, moral, physical and mental – and the multitude of long-term problems that can be expected to occur. Disabled adults who become disabled parents are still the disabled *children* of the family. Both the adult and his/her family continue to experience the problems of living with a disability in which the affected adult has very little insight into the nature of that disability. This

simply compounds the problems and costs facing the family trying to keep both their adult child and grandchild safe. At some point, this too, often becomes unworkable.

Studies looking at lifetime costs of FASD to society look at residential costs only for those with FASD who are mentally handicapped. Some studies only look at that cost to the age of 21, while two studies included this to age 65 for those with moderate and severe cases of mental handicap. In this latter case, 80% of the lifetime costs were related to this one cost alone. This is of interest, because it would seem logical that lifetime costs would be much higher for those individuals who are mentally handicapped, especially those whose IQs fall below 55 (the cutoff point for moderate mental handicap). However, in the absence of actual dollar figures for those services adults with FASD who are not mentally handicapped use in the absence of supported housing, we might think that only these adults are costing society a great deal of money. It is the position of this group that this would be a grievously erroneous assumption. Many adolescents and adults with FASD who are not mentally handicapped are getting their housing needs met through incarceration. Many are among the homeless with all of the attendant healthcare costs, substance use issues, petty crime, abuse, policing costs, cost to tourism and sustainability of our cities. Many lose their children to the foster care system. Many, if not most, are on social assistance of some form, living far below the poverty line. Many are involved in a revolving door type of rental-eviction-rental-eviction lifestyle in which damage deposits and belongings are lost repeatedly. Many are subsidized by family at great cost and to the eventual detriment of the family, resulting in loss of a support system for the adult. All of these are residential care costs.

Adults with FASD without any dependent children who receive the Persons with a Disability (PWD) funding in B.C. of \$786/month can expect to be paid \$433,872 between the ages of 19 and 65 (46 years) at current rates. Add the cost of medical premiums (\$29,808 over 46 years), minimal dental care (\$23,000 over 46 years), basic prescription coverage for psychiatric medications (averaged at minimum of \$150/month or \$82,800 over 46 years); and yearly bus pass (\$2,070 over 46 years). Minimum cost (46 years) to society is \$571,550.00 (\$12,425 per year) for social assistance support. The costs can only go up from here and will be borne by someone or some other system.

Lack of supported employment programs, job coaches, and vocational training mean that adults with FASD have no *legal* options beyond PWD funding and whatever monies family can contribute to their support. Research in this area has found that 80% of all individuals with FASD, regardless of IQ, are unable to *maintain* employment. Adolescents and adults with FASD, like all others, need a “reason to get up in the morning”, a job where they feel productive if only for a couple of hours a day, a week or a

few days a month. Many are likely capable of working at least part-time, or some of the time, or even all of the time, *if* the right supports and circumstances are in place. To accomplish this, one would need a funded campaign to increase awareness and understanding of adolescents and adults with FASD amongst employers. Support for employers as well as for both regular employees and the employee with FASD would be needed (i.e. job coaches available, employer incentives, financial subsidies etc.) The need to remove barriers to obtaining employment (such as homelessness, addiction, transportation etc.) are seen as interconnected to the issue of the employability of persons with FASD. In addition the need for built in mechanisms to assist with money management are also seen as essential to ensure that the necessities of daily living are paid for and to avoid the common occurrences of eviction, inadequate nutrition, health issues etc. which can directly affect the ability to hold a job.

Health care costs that society pays on behalf of adolescents and adults with FASD can be substantial. Lack of adequate diet due to inability to manage the tasks of budgeting, shopping and food preparation combined with a common lack of hunger leads to malnutrition. The inability to follow medical regimes or remember to take medications is an everyday occurrence. Safe sex is an oxymoron. Substance abuse is common. Rates of HIV and Hepatitis C are likely higher than the population norms. Mental health issues are overwhelmingly present and poorly managed. Schizophrenia *may* be more prevalent in FASD; bi-polar certainly is. Psychiatric hospital beds in B.C. cost between \$200 and \$600 per day. Any stress exacerbates anxiety and depression which often leads to more substance use which leads to more unsafe behaviour. High pain tolerance is normal. Untreated injuries and illnesses occur regularly leading to higher medical treatment costs. Circumstances that could have been managed in a doctor's office or clinic become admissions to hospital. Acute care admissions, depending on severity, can be enormously costly. Effective use of birth control is problematic, leading to unwanted and unplanned pregnancies, abortions, substance use in pregnancy, poor prenatal care and poor birth outcomes, all at high cost.

Addictions and alcoholism as disease processes run rampant in those with FASD who begin to use and do not appear to be amenable to any existing treatment protocols as presently designed. Yet those with FASD are referred to and admitted into costly treatment programs time and time again from which virtually none benefit, at least in part because these programs are based on the premise of intact neurological function. Detox beds cost between \$80 and \$185 per day and may refuse treatment based on the high number of times an individual has used it. Outpatient treatment services are waitlisted and others may go wanting while those with FASD fail to show up for appointments because they do not have the ability to

remember and get there on their own, but are expected to do so as a measure of commitment to change. All currently existing alcohol and drug counseling and treatment services depend on a deep intrinsic motivation to change, self reflection, insight and impulse control. As such, they are not appropriate for those with FASD, no matter the degree of addiction. Money spent on such programming could be better spent elsewhere. FASD specific alcohol and drug treatment needs to be developed, funded, piloted and evaluated.

Funded access to both assessment and diagnostic services for adolescents and adults was seen as a priority need. Many affected adults remain undiagnosed as a result of lack of financial resources. Participants talked about this as a violation of both the Canadian Charter of Rights and Freedoms and the Canada Health Act. They were unaware of any other medical diagnostic process an adult would be unable to access in the absence of money. Those who have had the luxury of a childhood diagnosis still require assessment services in adulthood, but few meet the eligibility requirements to obtain them and virtually none can afford them.

Adolescents with FASD may incur far less in the way of educational costs simply because many of them are no longer in school. However, for those who are still in an educational placement in B.C., most will have at least a 'learning disability' designation that has likely been with them since early elementary school. Many high school students with FASD who have managed to stay in school have designations allowing for higher levels of personal support, specialized programming or classroom placement, all at considerable cost. Depending on the designation, additional funding of amounts between \$6,000 and \$15,000 per student per year are available to a school (\$30,000 to \$75,000 over five years of high school; between \$72,000 and \$180,000 for 12 years of school) for a student *being maintained within a regular classroom setting*. Students who are in highly specialized or intensively supervised settings for students with mental handicaps or severe behavioural problems cost much more than that. However, the reality is that the vast majority of students with FASD receive little, if any, support to learn or keep them in school. The result is school failure, suspension, expulsion or drop-out. And with that, comes early involvement with drugs and alcohol, negative peer groups and criminal activity.

Students with FASD who do receive such supports are expected to require them for only short amounts of time, share the service with another child (or more than one); use the service only part time or on specific days, and to reach a state of function where support is no longer needed. Unlike other permanent disabilities, where support is funded on a long-term basis, individuals with FASD (and their families) are punished for not "getting better".

What is the cost to an education setting of not having the resources to provide an effective learning situation for a child with FASD? How much high priced time is spent dealing with behaviours, suspensions, families, outside agencies, writing reports, etc.? What is the cost to other students of a teacher's time spent not in teaching, but in trying to control a child who is overwhelmed, over-stimulated and under-served? What is the cost to society of a lack of education in an individual? What is the cost to society of not providing the same high cost supports to all students with FASD that are available to some? It is those supports that enable an adolescent with FASD to stay in school successfully – and staying in school on a daily basis provides a necessary structure to prevent involvement in antisocial activities of all types.

Adolescents and adults with FASD are usually financially dependent upon their families for a goodly part of their support, if not all of it. Few are able to maintain employment to a degree that would allow them to be self sufficient. While many do qualify for Persons with Disability (PWD) funding in B.C., they are completely dependent upon the actions of others to even begin the complicated access process for this assistance. While a token payment (\$105) for the assessment is provided to the assessor by the government, it is left up to the individual or family to make up the difference in cost of this assessment. The hourly rate that most people allowed to do these assessments charge is in the neighbourhood of \$150 an hour, and an average assessment can take anywhere from four to 10 hours and involves considerable detail that would only be known to someone intimately familiar with the individual. Many professionals are not comfortable doing an assessment on a client they do not know well.

The maximum amount payable monthly under PWD assistance is \$786. Others are not able to access even this small income as they are unable to undertake what is a complicated and onerous process without help and access to an "assessor". The shelter portion of PWD money is \$325 per month, with no subsidies available. This is an amount totally out-of-keeping with the cost of living in B.C., which has the highest housing costs in Canada and where rent for a tiny basement suite starts at \$500 per month if you are lucky. A yearly bus pass is available for \$45, but no provision is made for lost passes which must be replaced at \$10 per occasion (plus cost of bus fare for the six weeks it takes for a replacement). Medical coverage is provided, along with some basic prescription drug coverage. However, *many* prescribed medications are not covered, and whole classes of drugs are not obtainable for those on disability who cannot afford to pay for them. No over-the-counter medications of any sort are covered. Eye exams are not fully covered (\$75 fee; only \$45 paid and only once in two years), nor are replacement costs for eye glasses. Dental coverage is limited to \$500 per calendar year, an amount barely adequate for a check-up and cleaning. Costs of all other medically

necessary services (ie: physiotherapy, splints, orthotics, etc.) are not covered in almost all cases. Crisis grants are non-existent. A best-case scenario, after rent of \$500, leaves an adult with FASD, even if he had excellent budgetary management skills, with only \$286 per month for *all* other expenses: food, laundry, personal care, transportation, clothing, utilities such as a phone, medications, etc. This assumes the adult has no other bills of any sort, has absolutely no recreation, entertainment or personal life, does not smoke, drink or use drugs and never buys so much as a chocolate bar. In the absence of budgeting skills never in evidence with FASD, actual physical survival is dependent on the financial resources of others, either family or through the proceeds of crime. Even when the adult is living at home, this funding will not cover his costs.

Consistently, the inability to manage money, budget and avoid debt creates chaos in the lives of those with FASD, leaving family members to deal with consequences. Refusal to do so leaves the disabled adult at the mercy of others, hungry, homeless, taken advantage of and uncared for. Yet systems refuse to allow trusteeship of these very limited PWD funds in the absence of either agreement by the adult or a legal finding of incompetency. Even when such things as Power of Attorney or letters waiving confidentiality have been signed, they are not always honoured by different offices, agencies, companies and individuals. When a family does seek a finding of incompetency, and manages to acquire it, they become legally responsible for the actions of their adult child and all the costs that can entail. Finance companies, 1-900 numbers, internet scams, credit card companies, cell phone contracts, buy now – pay later offers, car leases, car rentals, – all take advantage of the gullible adult with FASD. Over and over again, potentially simple solutions to large problems are overlooked in the rush to practice a view of equality that fails to recognize that treating all people equally does not mean treating all people the same.

As well, the direct costs that able families absorb until they can no longer do so also include such high cost things as essential counseling and therapy, education and vocational programs, the costs of assessment and diagnosis, alcohol and drug programs, legal costs for adequate counsel and supervision costs for grandchildren. These are the types of services that may keep the adolescent or adult out of trouble and/or out of jail, but they are almost never paid for except by family. These costs are directly related to disability. They often come at a time in the lives of parents when they are least likely to be able to afford them – savings, lines of credit, loan possibilities and re-mortgaging have all been exhausted. Monthly income is stagnant, early retirement due to health concerns is a real possibility, and costs related to other children go unmet. What happens to the majority of families who never had the financial resources to start with?

For a break down of costs the family of an adult with FASD can expect to need to pay over time on a yearly basis, please see Appendix A.

The lack of financial resources to provide services and support to adolescents and adults with FASD and their families is seen as an area with dire and potentially fatal consequences. Lack of financial resources to support persons with FASD usually leads to social isolation, homelessness, victimization, criminal justice involvement, addiction, child protection concerns, mental and physical health problems, lack of vocational opportunities and family breakdown. The lack of recognition of FASD as a disability and the absence of the financial services and resources that go along with that recognition has been described as “systems abuse” by families. The true economic cost to society of not providing adequate financial resources to persons with FASD is far greater than the cost of proactive service provision.

There are also indirect costs to parents and families of persons impacted with FASD (i.e. serious stress and related health concerns for parents, loss of income due to costs associated with FASD, loss of property, lost opportunities, inadequate funds for other children, loss of parent time, loss of other children, social stigma and isolation, loss of extended family relationships and friendships, lack of personal safety, care of grandchildren, family and/or marriage breakdown, never ending grief, fear of what will happen to their adult child when they die, etc.). It is impossible to put a dollar amount to these things that largely constitute quality of life.

Health costs are enormous for both the parents and thus to the individual with FASD. The incidence of chronic physical and stress related mental health problems in parents is high leading to further loss of income. Participants described a “snowball effect” in which increased financial costs lead to increased health concerns, which then lead to increased financial insecurity and further health concerns. Family monies which should fund retirement and normal costs of ‘healthy’ children (ie: sports, lessons, education) are exhausted early on.

■ *“What happens to our kids when we are not here?”*

An issue of critical concern for parents and families is these long-term costs they are responsible for when no other funded services are available to them – *and which will continue to be incurred after their deaths*. Many parents support their adult children with FASD financially, physically, socially, and emotionally well into their retirement years, indeed until they are no longer physically able to do so, and the societal perception of the “golden years” of retirement and rest are no longer a reality for them. Parents have long since realized that the issues facing individuals with FASD are an unrealistic and unfair burden to impose on other family members and the cost of burnout filters through to everyone involved. Participants reported that often family and friends are not necessarily allies, and because of a lack of understanding, abandon families in need. There is a definite need for a “life plan” for individuals with

FASD that includes supporting families through the provision of a variety of respite and life-long support services as is done with all other developmental disabilities. In this respect, many feel we are light years behind those who are dealing with other disabilities (IQ below 70) and the cost to society is huge.

There is a need for a paradigm shift among all systems to see the value and cost benefit savings that could be obtained through the provision of realistic, funded supports within systems (i.e. social work, education, employment programming, justice, etc.). It is cheaper for society and communities to pay now in terms of providing adequate support services to individuals with FASD and their families. You cannot put off paying until some amorphous time in the future – today is already yesterday's future. The costs will not disappear as time goes on. Rather, in the absence of pro-action, the future cost of not providing services in the present becomes excessive (ie. hospital beds, prisons, etc.). Creative messages must be explored to reach all levels of service provision. Targeted, key issue training for all service providers and professionals must be mandatory. Key professionals must be identified to facilitate a greater and widespread understanding within their systems of the urgency of the issues facing adults with FASD and the *avoidable* high costs that are associated with continuing the status quo.

### Action for Change:

There is a critical need to develop a system of care for adolescents and adults with FASD that can adequately develop, fund, and implement a system of care that can adequately provide the following:

- Canadian studies that:
  - look at and include **all** direct and indirect costs associated with FASD to both society at large and the family;
  - determine actual and estimated cost to each system of care (education, social work, justice, labour, health, etc)
  - follow a large number of families and adults long-term with a view to costs;
  - contrast costs related to effective supports vs the absence of supports;
  - track the long-term health costs to parents of adult children with FASD
  - provide the “proof” that proactive long-term support is cheaper than reactive intervention
- Services and a service delivery system designed specifically for those with FASD across **all** domains – removing funding from other ineffective services may partially fund this, as would moving money from the legal system
- Access to all services based on diagnosis rather than IQ
- Adolescent and adult diagnostic services and updated assessments – mandatory coverage for costs as with any other birth defect
- Mandatory trusteeship of PWD funds by a third party
- Access to additional monies for support needs currently paid by families
- Innovative system of in-home support and respite for families
- continuing to provide for adult children, including 24 hour access to consultation and crisis help
- Crisis response teams that meet the needs of families rather than systems
- Provision of a broad range of counseling and mental health services to other family members

***The deployment of financial resources specifically targeted at FASD service delivery should be undertaken and considered a primary broad risk management tool for working with adolescents and adults with FASD.***

## Health / Mental Health

***“Her ankle was broken in three places but they let her walk to X-ray. They didn’t believe it was broken because it didn’t hurt.”***

***“The therapist said to him: You can use any language you want in my office. He replied: I only know English.”***

This group began with a discussion about the “denial of disability” that permeates all systems but is particularly problematic in the health care field. This denial, cloaked in the ethics of confidentiality, effectively denies individuals with FASD their basic human right to have access to appropriate and informed health care.

It has long been recognized that young children with FASD may have many health problems related to their disability, including aberrant immune responses, abnormally high pain tolerance, chronic infections, seizures, and additional physical alcohol related birth defects. ADHD is very common. What we have been slow to realize is that these conditions, which were manageable with good care, regular medical attention, nutrition, medication and on-going parental support and vigilance, are equally there in adolescence and adulthood. In fact, in the absence of such supports, health conditions deteriorate significantly in adulthood. Additionally, mental health issues such as anxiety and depression, perseverative disorders, eating disorders and problems with anger become common with the onset of puberty. As well, many adolescents and adults with FASD deal with dual diagnosis (either addictions or mental illness or both) grief and loss issues, attachment disorders, and post traumatic stress disorder due to abuse experiences.

In adulthood, many adults with FASD begin to undergo the developmental issues of young teens, at a time in life when the supports needed to support the process are no longer readily available to the individual. However, the assumption of society and its systems is that adults should be able to, and are therefore expected to manage the issues around health and mental care unsupported. The inclusion of parent advocates is essential for bridging the gap between individuals affected with FASD and health professionals who do not understand them, yet family is almost always excluded from health care and health care decisions. This is a potential prescription for disaster on several levels.

Physicians, health practitioners, nurses, psychiatrists, mental health therapists and counselors need to understand adolescents and adults with FASD in order to provide appropriate and necessary health and mental health services. At present, there is no consistent access to or dissemination of information on FASD within the medical community beyond basic diagnostic information. Even that is sketchy at best. The result is a population of 'difficult' patients who are viewed as non-compliant with care rather than as disabled. As such, they are denied the quality and quantity of care available to other disabled adults because their 'non-compliance' is assumed to be 'choice'.

It is the position of this group that access to funded FASD diagnostic services for adults is a basic Canada Health Act and Canadian Charter of Rights and Freedoms right that should be accorded to any individual suspected of having this disability. Denial of such access is a violation. Diagnosis should not only be made available but should be free of charge in accordance with all other medical diagnostic services in Canada. Diagnostic and assessment services should be comprehensive in nature as an in-depth assessment of the individual is crucial to providing information necessary to service provision. As well, updated assessments are required periodically, and should be funded. *It was noted that had an adult seeking diagnosis been assessed and diagnosed as a child, all of these services would have been covered up to his 19<sup>th</sup> birthday as part of a developmental disability. FASD, REGARDLESS OF THE AGE AT DIAGNOSIS, BEGINS AT BIRTH. It is not the fault of the individual that the diagnosis was missed in childhood. He should not be penalized for the failures of others.*

The lack of adequate health services provided to individuals with FASD is also a cause for concern. Individuals with FASD have many identified health needs which include dental issues, problematic nutrition and related needs, substandard immunity, mental health needs, vision, speech and language needs, motor control disorders, sensory integration problems, etc. High pain tolerance complicates most issues. Many individuals with FASD are also accident-prone and/or have resulting health difficulties due to their poor judgment and vulnerability. Many have, or develop, chronic health conditions. Many are unaware that they are sick and are slow to access medical care for their health needs in a timely manner, if at all. Medication monitoring services are seen as essential as many do not understand the need for or effect of the medications and are unlikely to consistently and appropriately administer them. Impaired memory makes this very much a 'hit or miss' affair at the best of times in the absence of support. Of particular note is the connection between sensory integration problems and poor dental hygiene and the subsequent need for extensive dental work. Poor state of dentition is also linked to further problems with

eating. Regardless of the medical issue, they are always assumed to be competent to understand, make decisions and anticipate and accept the consequences of those 'decisions'. In the absence of a finding of incompetency, parents are not informed or included in health care decisions or the provision of care, or the lack thereof. Yet they are the ones who will become responsible for dealing with the outcomes of those actions or inactions.

Health care needs cannot be well managed in the absence of a supported living situation. Since this is not currently a reality for many adults with FASD, creative ways will need to be developed to seek out these individuals and provide crucial health care where they are. For those adults who do have at least some measure of family or community support and stable living circumstances, physical health care services will need to include funded access to such things as Meals on Wheels, liquid dietary supplements, replacement of eyeglasses, medication reminder systems (people, not pill boxes), transportation to and from medical/dental appointments, and a medical interpreter/advocate/mediator. Adequately funded dental care will be essential to prevent further health deterioration.

The need for services in the area of sexuality/birth control was also identified as a significant health care need. Free birth control should be provided to all individuals with FASD. As instruction on how to use birth control properly is not particularly likely to be effective due to the disability, consideration must be given to options that do not depend upon the individual for compliance and for some, more permanent options. Many individuals with FASD do not understand the concept of safety with respect to STD's and often are in high-risk situations (i.e. prostitution, addiction etc.) due to their vulnerability and the ease with which they can be manipulated by others. There should be provision in place to provide support to individuals with FASD to safeguard them as far as humanly possible against STD's, HIV, Hepatitis C, etc. While not directly a health care issue, other victimization in the area of sexuality (i.e. internet/chat-lines, pornography, forced 'consensual' sex etc.) was discussed. Group consensus is that such acts frequently lead to involvement in the sex trade and the attendant health care issues.

In addition, assistance for children of adults with FASD is needed. Support is required to allow adults with FASD to meet the basic and emergency health care needs of their children. Failure to do this is considered neglect, and can lead to child apprehension. Access to daycare services that work with the parents affected by FASD and provide on-site health care to their children should be encouraged. This is particularly important when limited support is otherwise available. Services to protect the adult's right to parent with supports were also seen as a gap in service delivery.

Provision of such services would be a positive mental health support and likely help to prevent further pregnancies.

The consensus in this group was that the need for effective mental health services for adolescents and adults with FASD has reached a crisis point. Over 90% of all adolescents and adults with FASD will develop a mental health disorder. They are so prevalent in this population that FASD is now considered by many to be a precursor for mental illness. Generic counseling services are not effective, and may actually make things worse for individuals with FASD. Specialized treatment and counseling services able to address the individual needs of persons with FASD are essential and must be developed. They need to be available quickly, even immediately, as one “must strike while the iron is hot” when working with adults with FASD. At present, there are only a handful of therapists who specialize in adults with FASD, all of whom are in private practice and cost in the range of \$130 to \$150 per hour. Their experience and expertise must be shared and could form the basis of new ‘best practices’ for FASD and mental health. Adequate understanding and training of mental health clinicians can only lead to appropriate and more effective mental health treatment across the lifespan. Access to funded, appropriate, effective lifelong mental health treatment should be available. Typically, adults with FASD will need this support on a fairly regular basis, especially at times of stress and transition. Many individuals with FASD experience ongoing difficulties (loss of a family member, understanding limitations of the disability, loss of dreams/hopes, trauma, etc.). An interpreter for life issues is seen as vitally important in maintaining function. As well and wherever possible, a family member or support person should be involved in mental health treatment. The ability of this person to act as a ‘reality check’ for the therapist was seen as a pivotal role for providing good mental health care and services.

Increased understanding of medications and their affect on brain chemistry in FASD is crucial to providing primary mental health care. Yet science knows very little of the long term effects of these powerful medications on prenatal brain injury. Research in this field is an urgent need. Prescriptions for medication must be provided by a medical doctor, usually a psychiatrist, yet therapy is almost exclusively done by clinical psychologists. Often they have little knowledge about what the other is providing.

Mentors for individuals with FASD facing initial awareness of their disability may be helpful to their understanding. The availability of volunteer groups, buddy systems, and a hotline for individuals with FASD are also considered beneficial support services that are needed and should be provided.

Outreach services were also seen as necessary for mental health services. Individuals with FASD often have very limited self-awareness of symptoms and deterioration. The

willingness of professionals to provide mental health services to the adult with FASD where he is instead of waiting for the individual with FASD to come to him or access services on his or her own could improve the overall access to health services for these individuals. It might also improve mental health outcomes. The availability of a highly skilled “SWAT team”, or crisis intervention team to provide immediate mental health services to clients and parents is seen as THE key essential, as well as an FAS hotline where families could obtain immediate referrals for appropriate mental health care, (along with other health, legal, leisure/recreation etc. services referrals) and support for themselves. Additionally, a directory of professionals in various systems (i.e. health, mental health, legal, addictions, support etc) who understand and have both knowledge and experience working with individuals with FASD would be most valuable to parents/caregivers and other professionals working with individuals with FASD.

Parents of individuals with FASD also experience mental health issues for which they themselves require specialized support and intervention. Living with individuals with FASD is highly stressful at the best of times. At its worst, Post Traumatic Stress Disorder can develop as a result of chronically “living on edge waiting for the other shoe to drop”, persistent ‘parent-bashing’, and the lack of understanding from professionals, extended families, other children, friends, partners and individual parents themselves. The issue of “*systems abuse*” and its affect on the mental health of individuals with FASD and their parents is one that needs to be recognized and addressed. The results of bureaucratic denial and the subsequent, systemic punishment of parents/caregivers leads to parental exhaustion, the view of self as a failure in one’s role as parent and the development of severe stress related mental health disorders. This denial of access to necessary services has led to a widespread perception that individuals with FASD and their parents/families are “disposable” members of society.

### Action for Change:

1. There is an urgent need to develop a comprehensive system of physical health care delivery designed to meet the needs of adolescents and adults with FASD through:
  - Development and funding of comprehensive adult diagnostic and assessment services as a medical care *right*
  - Development of trained medical and dental teams to which individuals with FASD can be triaged for care
  - Development of a delivery system for care that is not dependent upon the adult for implementation
  
  - Provision of extensive outreach services that include medication administration of all types for all needs
  - Development of a system that will allow medical personnel in the field, hospital and other medical settings to know an individual has FASD
  - Development of clinical guidelines for medical assessment and treatment whenever an individual has FASD that mandate the involvement, wherever possible, of a third party interpreter and/or family member
  - Development of PWD, medical and other assistance protocols to fund medically necessary dental care, dietary supplements, vision care, and other medical treatment that is a result of birth defect disability at no cost to individual or family
  - Provision of regular in-home public health nursing services to parents with FASD to maintain and monitor the health and wellness of their children
  
2. There is a critical need to develop a comprehensive system of mental health care that is designed specifically to meet the needs of adolescents and adults with FASD through:
  - Provision of immediate access without a referral
  - Funding of actual costs for effective mental health treatment
  - Development and funding of highly skilled and FASD specialized mental health care teams to which individuals with FASD can be triaged (therapists, psychiatrists, social workers, trained volunteer supports, advocate, coordinator)
  - Development and provision of mental health outreach services and mobile clinics
  - Development and provision of “where and when” treatment models

- Development and provision of a SWAT model approach for crisis intervention services
  - Provision and funding of long-term mental health care needs arising *as the result* of a birth defect
  - Development of clinical practice guidelines for the mental health treatment of individuals with FASD that mandate, wherever possible, the inclusion of a third party support or family member as interpreter
  - Development of a process to determine 'best practice' treatment for FASD
  - Connections with drug manufacturers to encourage research into the specific effects and interactions of medications on those with FASD, and to strongly encourage the development of new medications designed for this population
3. There is an urgent need to provide mental health care services to parents and other family members through:
- Access to and provision of funded mental health counseling on an on-going basis as it is needed – and the recognition that the cause is FASD and not inadequate parenting
  - Provision of facilitated support groups
  - Provision of a 24 hour phone line that can provide information and support, and that has the ability to access immediate help for crisis situations
  - Provision of funded 'respite' services
  - Provision of a funded family advocate
  - Inclusion of parents in mental health care for the adolescent or adult

***The development and funding of targeted health care delivery and mental health treatment should be considered as a primary broad risk management tool for working with adolescents and adults with FASD. The provision of funded long-term mental health care to parents and other family members should be available, funded and encouraged as a risk reducing tool in the maintenance of essential supports to individuals with FASD.***

## Education / Programming / Employment

*“What are the two things an adult with FASD can do to be like everyone else? Have a baby or get a job. Where would you rather put your money?”*

*Dr. Ann Streissguth*

The lack of understanding and awareness of the specific needs *and abilities* of individuals with FASD among educational and vocational professionals is seen as a serious issue. Specialized education, pre-vocational and vocational training and supported employment practices are the pathways to successful employment and adult life for adolescents and adults with FASD. Yet cutbacks to funding have led to serious reductions in the availability of all special needs services that lead to successful outcomes for individuals with this disability, leaving them with no “reason to get up in the morning”. Adulthood is defined by the ability to “get a job”, and in its absence, an adult with FASD is left with far too much time on his hands and nothing constructive to do. Few qualify for CLS programs – those that do are the lucky ones. For the rest – the large majority – the desperate need to feel part of something – anything – invariably leads to victimization, trouble, pregnancy, substance use and criminal activity. The high costs to the individual, the family and society at large could be avoided at least in part through the provision of services to include those with FASD in the mainstream of life.

It seems obvious that keeping those with FASD in school during their adolescence is critical to future success. Yet, at the present time, 60% or more are out of school after the age of 12 because there does not currently exist the kinds of programming that identify them, understand the disability and meet their needs. Many adolescents with FASD remain undiagnosed in high school and there exists a significant need to develop a process to screen for the disability at this level. General FASD screening that could be administered when students are viewed as struggling academically **or** presenting with significant behaviour problems would be helpful for early identification of those who should be considered for further evaluation. In a climate of education cutbacks, referral for and access to diagnosis may be a necessary step in gaining entrance through one of the necessary “gates” to more appropriate school services. Even when it does not lead to services, it is still a tool to change the view of behaviour from one of deliberate choice to one caused by brain damage. Regardless, the diagnosis begins the process of directing the future.

While it may appear to anyone with a considerable degree of hands-on experience with FASD that these individuals are quite different from other learning disabled groups, it is not obvious to those absent this experience. There is a critical need to provide comprehensive information, education and hands-on support to teachers who have students with FASD in their classrooms. They need to understand the specific learning needs and learning styles and how to translate them into activities connected to the student's future. They have a critical need to understand behaviour in its proper context as the result of a severely impaired ability to function adaptively. A benefit of good awareness and education programs for teachers should also be a better understanding of family. Condemnation of parents as "over-protective" "over-controlling" "brooding" "enabling" or "enmeshed" with their children and the destructive interactions this sets off could be avoided.

Secondary school years are particularly difficult years that bring many challenges beyond academia to the individual with FASD (i.e.: vulnerability/victimization, peer pressure). There is a need to provide safety plans for such students as well as build in mechanisms to assist with transitions into secondary school routines. Structured programming that avoids free time and high risk settings should be encouraged. An allowance for repetition of grades is seen as beneficial or even essential in some instances when further reinforcement may be needed. The teaching of 'social skills' should be considered as a critical component of curricula and not an add-on for individuals with FASD. At present, there is no generally recognized programming for this that is not directed at mentally handicapped students. There exists a significant need to develop, pilot and implement such teaching directed specifically at those with FASD.

In addition, specialized programming is seen as vital (i.e. Industrial arts, practical components, applied career experience (ACE) programs, pre-vocational programs with job placements, life skills). An allowance for alternatives to conventional academia is both necessary and preferred. As well, all programming should be flexible, individualized, low stress and fully integrated into the community with built in transition supports. Serious consideration should be given to developing a model of education that re-thinks the purpose of schooling for this population to better address their long term needs.

A harsh reality for many individuals with FASD is that even existing services disappear after age 19 years. At this recognized 'adult' age, individuals are expected to be able to live independently, continue their education or find gainful employment, and start focusing on career goals and aspirations. The lack of realistic opportunities for individuals with FASD in the area of adult education and employment services is a huge gap in service provision leading to a bleak future. Individuals with FASD need

targeted employment opportunities that allow for a range of development possibilities. Careful and thorough evaluation of actual (versus perceived) strengths and abilities is essential. Full time paid work may not be an option for many, but part-time employment is. Those on PWD funding are permitted to earn up to \$400 per month without reducing their benefits. Access to this money could improve their living circumstances. Others may make effective volunteers in settings that respect their disabilities. Many will flourish in any setting that makes use of their talents and skills while modifying tasks and making allowances for their disabilities.

The availability of job coaches or “job buddies” is seen as a way to increase an individual’s ability to maintain a job. Employment settings that can provide a high degree of structure, routine and repetitive tasks work well for many. Job placements that are carefully matched between the needs of the employer and the adaptive abilities of the adult with FASD can allow success for both parties. Regardless, employers require training in working with all persons with FASD (ie. how to breakdown and sequence job skills in order to teach them to someone with FASD, how to communicate for comprehension, etc). They will further require training that is quite specific to the individual being placed or hired. Job coaches and job buddies will need patience, training, consistency and commitment.

Employers will need not only awareness of what supports are needed for the employee, but also the benefits of hiring someone with FASD. Socially conscious and responsible employers should be actively sought out, recruited and well supported. Incentives, such as wage subsidies should be available to employers who hire someone with FASD. Such subsidies should remain in place until it is absolutely certain that the job has been well learned and is being performed acceptably. The employee should continue to be attached to an employment program that can provide any additional support and skill-building required to be successful on the job. As well, cost free consultation services to the employer for problem solving over time could be useful in maintaining employment.

There will always be individuals with FASD, no matter how high the IQ, who are unable to meet the conventional requirements of typical employment. Expectations of employment need to be altered to allow for part time work, shared jobs, full time work for a while with a full time break without loss of employment, seven day a week work, and the like. For others, volunteer work, and social and recreational programming are essential. As with any other adult, those with FASD need regular productive activities they can be part of. Funding for such programming will be required as few adults with FASD qualify for existing CLS programming of this type. As well, it will pay to remember that those with FASD are distinctly different from others with handicaps, and programming that has been effective for them will not

necessarily work with this group. These 'high functioning' individuals require programming that does more than 'fill in time'.

Programs that address indirect employment-related needs of persons with FASD are also needed. These include money management services, life-skills coaching and mentoring, at work relationships, problem solving, advocacy and interpreter services etc. These are essential services to assist the individual with FASD not only in obtaining a job, but are crucial in maintaining one. Many individuals with FASD are fired from jobs not because of their ability to do the job itself, but because of the lack of life and social skills support required to keep the job (ie: appropriate dress, unspoken rules of the workplace, lateness, fleeing when things get difficult, not asking for help, bad debts, eviction, addiction, etc.).

No matter whether or not adolescents and adults can be maintained in school or employment, society must remember they are disabled citizens. As such, they should be eligible for, and able to access dedicated programs such as those available to all other developmentally disabled Canadians.

### **Action for Change:**

There is an acute need to develop and fund a comprehensive range of educational, vocational, employment and other programs for adolescents and adults with FASD through:

- ❑ Creation of a education system funding category for those with a diagnosis of FASD
- ❑ Development of and implementation of an in-school screening protocol and referral system for diagnosis
- ❑ Triaging diagnosed students into specialized teaching teams in designated 'expert' schools
- ❑ Design, development and implementation of a new vision of vocational education for high school students with FASD that works closely with community, employers and adult education systems, incorporates life and social skills as mainstream curricula and mandates transition services
- ❑ Continuing to provide and fund education placements for adults with FASD past Grade 12
- ❑ Development and funding of FASD specific vocational skills college programs that can provide tutorial and academic supports and job placement services for those able to undertake this
- ❑ Development and funding of "FASD employment service" programs with the resources to:
  - recruit, train, retain and support a wide range of employers and employment activities
  - thoroughly assess actual (versus perceived) abilities
  - carefully match employees needs to employers needs
  - provide on-the-job training and coaching for as long as, or as often as necessary
  - provide on-site and on-going consultation to employers
  - provide classroom and other program support to those with FASD to address indirect job skill issues
  - create and manage entrepreneur type job settings for those with FASD who may have special talents
  - provide and support a range of options in terms of hours of work, how work is done, days of work, job length, etc

- Development of a range of other volunteer, social, recreational and life skills programming to meet the daily needs of those adults with FASD who are unable to be employed

***The development and funding of targeted educational, vocational, employment and other programming that is specific to adolescents and adults with FASD should be considered as a primary broad risk management tool. It should also be considered as a risk reduction tool in its ability to help maintain both residential and family placements and to provide 'respite' to parents.***

# Legal & Addictions

***“There is no Justice System; there is a Legal System”***

**(B.C. Provincial Court Judge)**

This session began by considering the connection between substance use and criminal activity. As noted by the larger working group, the two are almost always linked together. If substance use happens first, criminal activity will almost certainly follow. If criminal activity happens first, it brings the individual with FASD into contact with those who are committing crime to support a habit. In either case, one leads inexorably to the other. Experience has taught those working with FASD that once involved with either, adolescents and adults with FASD will very likely spend their adult lives enmeshed in the criminal justice system. This is not a resilient population. The best possible solution for those with FASD is to prevent substance use and criminal activity to begin with. This requires services, supports and programs not currently available. To that end, the group posed four questions: “what is the legal definition of an adult?” “what is the legal definition of disabled?” “what defines independence and autonomy?” and “how do these things impact on the legal and addiction systems?”

If one is to look up the definition of the word ‘adult’ in any good dictionary, it will be defined as “fully developed and mature”.<sup>1</sup> This clearly does not fit for adults with FASD. But neither are they considered by society and its systems to be children because they are, in fact, over the age of legal majority, as that is defined in the jurisdiction in which one lives. However, if one also looks up the definition of the word ‘child’, an interesting definition is provided (beyond the obvious) as “one strongly influenced by another or by a place or state of affairs”<sup>2</sup>. This is much more in keeping with the functioning abilities of adults with FASD, who adaptively, usually function in the moderately mentally handicapped range. However, society has no ‘test’ that is automatically given to every adult on his birthday to determine whether or not he should be an ‘adult’. Perhaps it should.

Traditionally, an adult is considered to be anyone over the legal age of majority, which in B.C., is 19 years of age. In the legal system, 18 is used as the age at which adult penalties are imposed. In the health care systems, the age at which a child is deemed competent to refuse treatment (including for substance use) or medication can be as young as 12. The age for sexual consent is 14. Independent living

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<sup>1</sup> Merriam Webster’s Deluxe Dictionary, 10<sup>th</sup> Collegiate Edition; 1998

<sup>2</sup> Ibid

situations for youth in foster care begin at 16 and are strongly encouraged as a cost savings measure. Police are reluctant to look for anyone over the age of 12 who is a runaway. Why these ages? Because, there is no legal definition of an “adult”, Society and its systems have decided that individuals have the ability to understand the consequences of their actions at these ages and are competent to make those choices. And it is always assumed that a ‘choice’ is being made, even though those with years of experience with adolescents and adults with FASD know that ‘choice’ is rarely ever involved: “things just happen”. Age does not match behavior.

It is clear that adolescents and adults with FASD are disabled. But what, exactly is meant by that? And if this is generally accepted, then why does this status not lead to services? Currently, the only standard by which disability is measured in FASD is IQ below 70, or mental handicap. However, the dictionary defines disabled as “made incapable or ineffective and *especially*: deprived of physical, moral or intellectual strength”.<sup>3</sup> This would appear to be a particularly apt description of the range of deficits seen in FASD. Yet it appears that society believes this is a ‘deficit of character’ rather than a result of brain damage. And as long as society can cling to the position that this is character based, it can justify refusing supports and services to a group it does not see as deserving. Thus a disability is not a disability.

It is equally clear, and supported by research, that at least 80% of those with FASD will be unable to live independently, regardless of IQ. So we must ask “what does the ability to be ‘independent’ entail?” Again, we turn to the dictionary for a definition of the word and find the following: “not subject to control by others; self governing; not requiring or relying on something else; not looking to others for one’s opinions or for guidance in conduct; not requiring or relying on others (as for care or livelihood)”.<sup>4</sup> Autonomy and autonomous function is the goal to which society insists all learning and activity be directed. It is defined as “undertaken or carried out without outside control; self contained; existing independently of the whole; the quality or state of being self governing; self directing freedom”.<sup>5</sup> How ironic that the commonly repeated statement “It takes a village to raise a child” should be so ignored for our adult children.

Once an individual with FASD turns 19, they are always considered to be functioning adults able to live and work independently without supports, no matter their IQ, their adaptive functioning limits, their diagnoses – and no matter what level of support they may have had during childhood and adolescence. On a 19<sup>th</sup> birthday, everything stops. The only allowance for even limited services is for those individuals with an IQ

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<sup>3</sup> Ibid

<sup>4</sup> Ibid

<sup>5</sup> Ibid

below 70. For the majority of adults with FASD, this criterion does not apply, yet they also do not meet the definition of independent, autonomous adult by any standard.

***If an individual with FASD does not fit the conventional definition of 'adult (ie fully developed, mature, able to live independently etc.) and they do not meet the socially accepted definition of developmentally disabled (IQ below 70), where do they fit? And who provides services to a population caught in limbo?***

Into this huge gap steps the criminal justice system. It is the only system that has a very simple eligibility requirement: commit a crime and you are automatically eligible for service provision. Forget your IQ. Forget your diagnosis or lack of a diagnosis. Forget your age. Forget the need for an assessment. Forget the fact the 'program' is full. Forget your family income. No need for a referral. No waiting list. "Come on in and we will provide you services because we don't have a choice in the matter". How ironic and short-sighted that the most expensive option for support is the only one always available.

The criminal justice system has become, by default, the social safety net for adolescents and adults with FASD. As such, there is a need not only for increased awareness and education about FASD among justice professionals and systems (lawyers, judges, corrections, police etc.) but for highly skilled staff who will be working directly with these individuals. This training should be mandatory for front line professionals in both legal and addictions systems. It should focus on recognition of the indicators and manifestations of disability and the likelihood of involvement in criminal acts as a result of disability rather than deliberate behaviour. A strong focus on understanding FASD as brain damage non-competence rather than conduct disorder and/or non-compliance should be emphasized. Staff working directly with those with FASD should be hand-picked for a specific skill set, patience and high tolerance for frustration. They must be provided with extensive training in how to work more effectively with this population and access to consultation services.

There is a need for FASD specific interpreters within the justice process who are available to both the individual and the system. Many individuals with FASD do not understand the legal process, especially as it relates to their basic rights. Violations of these rights occur regularly, not because the system does not care, but because the system does not understand the disability. This is particularly a problem when presented with an adult who talks well, looks good and cops an attitude. The reality that the individual understands little of what is said to him is easily missed. Many adolescents and adults with FASD may incriminate themselves, or provide false statements because of their lack of understanding. They have little concept of time, poor memory and are easily confused. Interpreters should also be available for the court process so that the

individual with FASD understands their plea and disposition and is able to answer questions posed to them by the court. These questions may need to 'translated' by the interpreter. The mental health courts might be a potential model that could be more 'user friendly' for individuals with FASD. However, a challenge to this is the absence of FASD in the *Diagnostic and Statistical Manual on Mental Disorders (DSM-IV)*.

As there are Native Court Workers available in the courts, so too should there be FASD Court Workers readily available on-site to provide assistance and support to individuals and families affected by FASD. In addition, the issue of confidentiality in the legal system poses a challenge to parent-advocacy in the court process and must be dealt with. Modifications should be made to allow for a parent/caregiver to support and advocate for the individuals with FASD. Access to specialized and affordable legal services to assist with defense should be provided. Currently, parents/caregivers who want to advocate for an adult with FASD do not have the right to access information or, in most cases, to provide information to service providers. This is exacerbated when the individual with FASD is also resistant to parent involvement because of their understanding or misunderstanding of the rights of an adult, but at the same time, has no idea how to help themselves and relies on the parent for complex issues.

Access to funded diagnostic and assessment services is also a need within the legal system. As the legal system is a catchment basin for undiagnosed individuals with FASD, it is a pivotal place for identification. A referral for diagnosis should be mandatory before sentencing in cases where crown, defense or judge suspects FASD, or the family presents evidence of the likelihood. It is likely a *Charter* violation to ignore this.

A mechanism to 'flag' individuals with FASD within the legal system might serve to increase awareness and understanding of their specific needs. In addition this would facilitate communication among justice professionals. One way to do this would be to use the Canadian Police Information System (CPIC), a system that justice professionals have access to that identifies whether someone has a criminal record, outstanding warrants, etc. This flag would then inform justice professionals that specialized intervention and protocols are required with the individual from the point of arrest onward. This flag would identify an advocate, family member or service provider who must be called, regardless of the age of the individual. Ideally, a specialized police unit could be called in to provide specific services to the individual with FASD. There is a caution in using such a mechanism in the possible occurrence of discrimination or hurt caused to the individual with FASD as a result of this information. However, it is also the undeniable reality that individuals with FASD are already discriminated against and flagged for negative attributes that are likely the result of a lack of knowledge about the disability.

Alternatives to incarceration are critically needed for individuals with FASD who enter the legal system. Prison merely puts them in with bad people and exposes them to even worse abuse. It never makes them a 'better' criminal; they always get caught; and they do not learn from the experience. A disability version of restorative justice initiatives may be a more effective alternative. It would have to be significantly adapted as this model which focuses heavily on 'accountability', may be problematic given the limits of this disability. However, it is also focused on a less punitive approach. Since individuals with FASD have great difficulty learning from their experiences and applying that information, traditional sentencing which increases penalties each time an individual is convicted should be contraindicated. It is ineffective at best and abusive at worst. *Community Circles of Support* is also a program that could potentially be adapted for those with FASD who have been in jail.

In addition, specialized programs and facilities for individuals with FASD are also needed. For those who are incarcerated, specialized units and teams that are trained in working with individuals with FASD should be utilized. Advocates should be made available at all stages of the justice process. Realistic transition planning and aftercare services must be available in the community. Specialized probation and parole services that understand FASD must be developed. FASD protocols and risk management tools must be developed to provide realistic expectations and supports. Flexibility is required to avoid persistent breaches and additional time in custody for what are disability related behaviors.

Substance use treatment services that have proven to be effective for those with FASD do not exist - anywhere. Very little emphasis has been placed on modifying, developing or providing treatment services for people with any developmental disabilities in any case, let alone FASD. FASD particularly poses and will continue to pose a very significant challenge to the addiction treatment system. Adolescents and adults with FASD are highly deceptive in their appearance of function. Their 'savant like' ability to talk well, works against them. We live in a society that believes when a person talks well, they think well. Individuals with FASD *appear* to be able to think, understand, plan, organize, develop insight, remember and follow through, but appearances are very deceiving. Traditional, language-based insight counseling methods (equally ineffective in mental health) are not appropriate for those with FASD. Thus treatment approaches and programs based on such cognitive abilities are bound to fail. It is not the individual with FASD who is failing at the program; it is the program that is not working for the individual. It is not a matter of modifying, 'chunking', repeating or restructuring existing programs. New approaches must be developed from the ground up. Considerable thought and expertise in the area of FASD and substance use needs to be involved in deciding what the actual reason for and goal of treatment is, for those with FASD, and

how that might best be accomplished. Clarity of purpose is needed. Reality must be faced. And until these things come together, little is likely to change. Scarce resources will continue to be used with little benefit.

Once an individual with FASD enters existing addictions services, there are specific structural systemic problems that arise. The length of a residential treatment program is inadequate and must be longer than the usual 30 or 60 days. Location of residential programs is often a problem. There is a critical shortage of detox beds; an access system that is almost impossible for those with FASD to undertake; waiting times; a lack of ability to transfer directly from detox to residential treatment; no transitional care into the community; no follow-up services or supports. In addition, multiple barriers, such as discrimination, victimization and outright refusal of service due to “over-use” and perceived “lack of commitment to change” need to be addressed. Some recovery houses operate on the fringes of legality. ‘Zero-tolerance’ policies and point systems in effect in almost all facilities set up individuals with FASD for failure. They are ineffective and not based on a realistic model of addiction, especially for persons with disabilities.

There is a critical need to design and develop non-punitive, supportive residential treatment, counseling and support services for pregnant women who have FASD and are dealing with substance use issues. Women who are pregnant must be prioritized to get into treatment centres. Second generation FASD is fast becoming a serious problem. It is a definite challenge for any woman who is pregnant to access addictions services that provide support without threat of child apprehension. For the woman with FASD, the threat becomes a reality. There is a *very* high probability that she will lose her children if she tries to access help. If she fails at either outpatient or residential counseling (and that likelihood is almost 100%), she *will* lose her children and the baby at birth. Already overtaxed family will have to step in or risk permanent loss of grandchildren. Such insistence on the part of systems that she ‘succeed’ at a program guaranteed to cause her failure is short-sighted, punitive and cost prohibitive in the long term.

It seems so obvious that it is almost not worth saying, but there is a need for prevention and intervention services *before* addictions arise. This includes access to leisure/recreation services and programs, mentorship and positive peer support programs, vocational/volunteer opportunities, opportunities to get involved in community activities that are healthy, pro-social and completely avoid alcohol and drugs. For those few individuals with FASD who may pose concern to other individuals, there should be access to 1:1 supervision and support programs that meet their unique needs. Substance use in FASD is so poorly understood and even more ineffectively treated that money spent aggressively preventing it in the first place would be well spent.

### Action for Change:

1. There is a critical need to develop a true *system of justice* for adolescents and adults with FASD that crosses jurisdictions, systems, and authorities. Such a system would provide for:
  - Development and implementation of new definitions of developmental disability that are not IQ dependent, which more accurately reflect, legally acknowledge, and effectively support adolescents and adults with FASD
  - Legal recognition that all birth defects involving congenital developmental disability, regardless of age at diagnosis begin at birth. As such, supports that would be automatically accessible by any other person with any other developmental disability birth defect should be available to those with FASD
  - Design, development, and implementation of a national campaign to shift public perception, remove stigma, and support adolescents and adults with FASD to contribute positively in the mainstream of Canadian society, as we do for those with other recognized disabilities
2. There is a critical need to develop, fund, and implement legal services for adolescents and adults with FASD which will:
  - Provide a range of information for people employed within the legal system, not only awareness and education, but also mandatory comprehensive training for those working directly with individuals with FASD on a daily basis
  - Develop and employ stringent selection criteria for the recruitment and deployment of staff, contractors, and others working directly with affected adolescents and adults
  - Develop, fund, and implement a FASD court worker program and provide access to qualified FASD interpreters at all stages of the legal process
  - Develop and implement appropriate FASD protocols for all systems of the legal process that mandates how the individual must be dealt with because of the disability
  - Develop and implement a mechanism that identifies individuals with FASD within the Canadian Police Information Centre (CPIC) in order to affect the appropriate FASD protocols
  - Provide and fund access to diagnosis as required as a *Charter* right at any step of the legal process where suspicion arises
  - Develop and fund alternatives to incarceration for the majority of those with FASD who are not violent offenders. These alternatives must not be dependent on house arrest which uses families as jailers

- Develop and implement specialized units and programs within institutions for incarcerated individuals with FASD, when other options are not available or have not been effective, which include proper transitioning to community services
  - Develop and implement specialized parole and probation services for released individuals with FASD who return to the community
3. There is a critical need to develop, fund, and implement addictions services for adolescents and adults with FASD, that will:
- Provide for and fund research to determine what is different, if anything, about substance use and addictions in this population
  - Further design, develop, fund, implement, and evaluate models of substance use treatment for those with FASD that may be more effective
  - Provide long-term follow-up to determine which models are most effective for relapse prevention
  - Provide priority access, non-punitive, supportive residential treatment, counseling and support services for pregnant women who have FASD and are dealing with substance use issues

***Involvement with the legal and addictions systems occurs when other risk reduction strategies have been ineffective for a variety of reasons. However, because it is in the position of having to provide services to individuals with FASD regardless, it could also provide a pivotal intervention point. The development and funding of targeted legal and addiction services that are specific to adolescents and adults with FASD should be considered as a primary risk management tool.***

## Family Support

***“My child was born with a disability. It is society that handicaps him. It is society that handicaps us.”***

*(Handicap: “a disadvantage that makes achievement unusually difficult”)<sup>6</sup>*

Regardless of how it is constructed, children are supposed to grow up in a family. In the normal course of events, and in the normal course of development, those same young people leave home some time between the ages of 19 and 25, depending on circumstances. This is the age when these adults are in post secondary education or gainfully employed, self-sufficient, responsible, respectful, socially engaged, self-directed, self-controlled, self-monitored – in other words, functional adults. They do not require the daily support of their parents. They do not need supervision. They can be trusted. These adults stay in the home as long as they do, not because they need to but because they want to. They are financially able to take care of themselves and manage their own affairs. While parents may not always agree with their decisions, those decisions are not dangerous to them. When they make a mistake, they are able to rectify the situation and learn from the experience. The decision to continue to live at home is mutually agreeable and generally works well on both sides of the equation. Parents often have the added benefit of observing first hand how well a child has turned out. The stresses are only those involved in the normal everyday course of events that happen when older people live with younger people. No matter the negative circumstances of the moment, the parent *knows* it is only a temporary blip. And parents *know* that eventually, the adult will move on with his life, and leave home, allowing them to get one with theirs. And most importantly, if for any one of a number of reasons they must ask that adult to leave the home, they *know* that adult child will be able to survive without them and do so in almost all cases, in a lawful and socially acceptable manner.

Intact families living with normally functioning adult children are not in need of support services. They do not need ‘respite’ or a ‘break’ from their children. They have not experienced many years of on-going extremely high stress levels. They have continuing access to disposable income that has not been gobbled up by a disability. They have not been forced over and over again to make choices that pit the needs of one child against the wants or needs of another. They have not been held hostage

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<sup>6</sup> Merriam Webster’s Deluxe Dictionary, 10<sup>th</sup> Collegiate Edition; 1998

to experiences for which they could never have been prepared. They have the privilege of a life which is separate to that of their children.

The story is very different when the adult son or daughter has FASD. The adaptive functioning and developmental levels of these adults are those of much younger children, but society insists they be accorded the freedoms of an adult. They are not self directed and self controlled; they are most certainly not self sufficient and require daily support in all the areas of life; they *must* be supervised or things can go terribly wrong. The safety of everyone is frequently an issue, even though violence is not. They *cannot* manage money and have little concept of value. They are chronically manipulated by those who take financial advantage of them. Many have serious problems with mental health issues; a goodly portion develops substance use problems. Even more are out of school after Grade 8 and very, very few are employed even occasionally.

The financial burden of care for this disabled adult falls on the family *far* beyond what should be expected or is reasonable, and in ways that families with other disabled adults never experience. Financial care costs go up, not down, and can be such a drain on parental resources that continued care is not viable. PWD funding is not automatic, the process is arduous and costly, and no financial management services accompany it, making it of almost no value to a family even when approved. Support and service systems that may have been accessible or of some use in childhood disappear. The few effective resources available are costly and out of reach to most to begin with, and to all, sooner or later. Attempts by family to continue to keep these adults 'safe' are often viewed as enabling behaviour that is actively discouraged by systems that believe these adults *must* learn from experience. Personal family support falls by the wayside as extended family; friends and community systems turn away due to the chronic nature of the difficulties encountered and the 'lack of change'. Slowly and insidiously, the stress of always 'living on the edge' becomes unbearable and unmanageable with all the attendant physical and mental health sequelae for parents. Keeping them safe means 24/7 support which is time consuming and takes enormous energy. There is no end in sight, not ever. And whether or not they can be maintained in the family home or must live elsewhere, they will continue to have *high* needs for support – financial, social, moral, mental, emotional, psychological, programs, etc.

Children with FASD become young adults with FASD become middle aged adults with FASD become old adults with FASD – and they *always* have FASD. While their needs may change over time, there will *always* be needs. Disability is not a temporary condition and, makes no mistake; this is a disability quite unlike all others.

Intact families of adolescents and adults with FASD are a testament to the level of strength, resiliency and commitment these parents have to one another and to their children. A sad reality is that other families are intact, in many ways, only in that they continue to live together, because they feel they have no choice. Still others simply do not survive the experience. Regardless, all know and understand pain on a level most people would find intolerable. Denial, abandonment, anger, disbelief, hostility, victimization, grief; self blame; all are no stranger to the parent. And in the end, *each one* comes to the end of the road. There is no safety net.

And it is all so unnecessary. There may be, at the present time and in the lack of targeted and funded direct services to FASD, no way to prevent the level of difficulty many adolescents and adults experience. However, there is no excuse for the lack of support available to the family. Family support services of all kinds are readily available to those with other disabilities. They exist, and are funded, because they *are the right thing to do* and because they save society money. Support is the primary reason families are able to continue to (1) provide for the emotional needs of each other; (2) advocate for their child; (3) provide for financial needs of their child; and (4) continue to be involved on a positive, on-going basis in the lives of their children no matter where that child might be. Parents have also long since understood and accepted that the issues facing individuals with FASD are an unrealistic and unfair burden to impose on siblings now and after parental death. Where does that leave them; especially when one considers the health problems in many parents and that an early death is not unlikely? These are not minor concerns.

Support is a cost effective way to help families help their children, and the needs for these supports are known from infancy onward. Much of the information in this document is 'old news'. Families, systems, and governments have known for at least the last 15 years that this is the case. This was well documented in the 1992 Health Canada report "*Report on the Symposium on Fetal Alcohol Syndrome and Fetal Alcohol Effects*" held in Vancouver, B.C., and very, very little has changed since that time. And while things remained 'as is' another generation of children with FASD became adolescents and adults. The Health Canada FAS/FAE Initiative "*National Synthesis Report*" of June 2000 reiterates this same information in even greater detail.

The results of legislative and policy inequities, the lack of system resources, bureaucratic denial and the subsequent, systemic punishment of parents/caregivers comes at a high cost to society. This denial of eligibility for and access to *essential* services has led to a widespread perception that individuals with FASD and their

parents/families are somehow not deserving, not disabled and not worthy of our efforts. This is unconscionable.

**Action for change:**

There is an urgent need to continue to develop and fund family support services that can help to maintain or repair family systems that may be in addition to and separate from those already listed in previous sections of this document, by:

- ❑ Consulting widely with families to determine needs and most effective ways to meet them; this consultation process must seek out and be inclusive of all families in all areas of the province, urban, rural, remote and on-reserve; with specialized emphasis on the different needs of different types of families
- ❑ Development of a Standing FASD Consultation and Steering Group on Adolescent and Adult Issues to government which includes both highly skilled professionals in this area and parents as primary members, along with representatives from every ministry of government, with the authority to commit resources. This committee would be mandated to direct the development of services for those with FASD, and be accountable for them
- ❑ Formation of an Office of FASD similar to the Office of Service Equality for those with mental handicaps
- ❑ Formation of a new ministry specifically to deal with FASD, in which could be combined and nurtured the requisite knowledge, skills and abilities to make a difference; and where 'all doors are the right door'
- ❑ Striking of a task force commission with the power to make binding recommendations for systemic change to accommodate those with FASD
- ❑ Development of a mechanism to maintain a very high profile on the issues of adolescents and adults with FASD and their families; and to focus this as an issue of *disability, basic human rights, equality, equity, dignity and respect*.

***The development and funding of consultative processes that have the authority to direct monitor and evaluate changes specific to the support needs of adolescents and adults with FASD and in particular, their families should be considered as a primary broad risk management tool.***

## Summary

***“You see a snapshot of my child – I live the movie.”***

FASD is a sustainability issue for society. No matter whom you are, where you live, what you do, what you think; FASD will touch your life. It is not a question of ‘if’; only ‘when’. It is common and very costly, both financially and in terms of human suffering. And while it is also preventable, we have miles to go before that is anything more than a glimmer on the horizon. It is so much easier to see alcohol abuse and alcoholism as character flaws rather than a disease process. It is so much easier to see FASD as bad behaviour by choice, the result of poor parenting. As long as society – and we are society – clings fast to these beliefs it will continue to encourage and participate in that “looming social tragedy of epidemic proportions unprecedented in Canadian history.” Until society learns to resolve its love-hate relationship with alcohol, those who become addicted to it and those who become its victims, it will continue to ignore rather than treat, punish rather than support, and cast out rather than gather in.

This is the challenge to all of us: what is it going to take to get each and every one of us, the multiple systems and levels of government that we, in fact *employ*, and all parts of *our* society, mobilized, organized, able and willing to deal with this issue? To remove the *handicaps* that so negatively impact on the lives of those with FASD and their families. Not just talking about it, but actually doing what needs to be done in a comprehensive, targeted and meaningful way.

What will it take to allow the adults with FASD of today – and all the children who will become adults tomorrow - to live, partake, contribute, belong and enjoy life in the mainstream - in other words to have what the rest of the world takes for granted? To do anything less is unethical and unconscionable in any society that truly believes in equality.

*If the misery of our poor be caused not by the laws of nature, but  
by our institutions, great is our sin.*

*Charles Darwin*

## Costs the family can expect to experience over time for an adult with FASD

### *Sources of income to meet costs:*

An adult with FASD in B.C. has three legal sources of cash income he can access (with help) in the absence of employment or complete support from family. They are as follows

1. income assistance (welfare) of \$500 per month
  - a. must have lived away from, home for two years before one can apply
  - b. can only be collected for two years out of every five
  - c. there is a list of exceptions to the two year rule, none of which would readily apply to an individual with FASD
  - d. has a lifetime limit
  - e. any fraudulent conviction leads to lifetime disqualification
  - f. no benefits of any sort with it
2. Persons with Persistent Multiple Barriers to Employment funding (PPMB) of \$600 per month
  - a. Primarily for those with alcohol and drug problems sufficient to prevent them working in the absence of effective treatment; those without *any* education; etc.
3. Persons with Disability funding (PWD) of \$786 per month
  - a. See previous discussions; for those considered to be unemployable; is subject to review every few years

- b. Note: if living at home and paying room and board versus room rent; only the room and board amount is paid plus a small “comforts allowance”

**Basic** monthly costs of living for a single adult with FASD trying to live alone in a **best case scenario** are as follows:

<b>Basic Item</b>	<b>Receiving PWD</b>	<b>No PWD</b>
Rent – basement suite (cheapest accommodation)	\$500.00	\$500.00
Food, hygiene and household supplies (does not include laundromat cost); assumes can budget, shop; access to large grocery store; prepare and cook food	\$200.00	\$200.00
Utilities such as heat, light, cable (does not include internet or phone costs)	\$100.00	\$100.00
Medical premiums		Premium assistance available to those with limited income
Dental care (minimum amount possible to pay for check-up and cleaning yearly; no allowance for any other dental services)		\$60.00 (averaged amount available to one on PWD)
Transportation (2 zone bus pass); does not include costs of 3 zone pass	\$ 50.00 (averaged cost of replacement for lost passes and bus use in absence)	\$120.00
Cell phone (cannot meet requirements for a landline)	\$100.00	\$100.00
Prescription medications (antidepressants, anti-anxiety, psychiatric)		\$150.00 <b>minimum</b>
Clothing and shoes (replacement of worn out, lost, destroyed, stolen items)	\$100.00	\$100.00
Haircut (male)	\$ 15.00	\$ 15.00
<b>TOTAL COST PER MONTH</b>	<b>\$1,065.00 = MONTHLY DEFICIT OF \$279</b>	<b>\$1,345.00 = MONTHLY DEFICIT OF ???</b>

This assumes no other costs. In actuality, over the course of time, parents can expect to cover the costs of the following items, depending on the individual, the circumstances and situation of the moment:

ITEM	COST ESTIMATE PER INDIVIDUAL TO FAMILY
The overage from the above	\$279.00 per month or \$3,350 per year
Eye check-ups	\$75.00 per year
Prescription medications not covered (all brand name, non generic; any anti-inflammatory, any sleeping medication; <b>many</b> antibiotics; most allergy sprays and medications)	\$800.00 per year
Non-prescription medications, melatonin, first aid supplies; antibiotic creams, cost of crutches, etc.	\$600.00 per year
Physiotherapy, chiropractic, occupational therapy (limited to only 12 combined visits each year for <b>all</b> services outside doctor for PWD)	\$50.00 per visit after 12 PWD visits; could amount to \$500.00 per month for any one service
Splints, orthotics, braces, eye glasses, (replacement costs; some initial costs due to limited coverage for PWD; all costs for others)	\$1,000 per year
Dental care for cavities, etc. over \$700.00 PWD funding	\$2,000.00 per year on average
Dental appliances and replacements (initial cost for appliance <i>may</i> be covered; approval process can take 6 months or longer)	\$1,000 per year
Oral surgery (wisdom teeth)	\$1,500.00 and up
All anesthetic costs for any outpatient surgery	\$300.00 per occasion
Birth control	\$ Variable, some covered – some not.
Mental health therapy utilizing a skilled therapist knowledgeable about FASD	\$140.00 per hour; some may be covered under Residential Historical Abuse Program funding or Criminal Injuries Program (about 50%); best estimate per month is between \$280 and \$560.00 per month, with crisis intervention costs ranging much higher. <b>Note:</b> most individuals with FASD receive no funding under RHAP or CICP
Food supplements that may be essential to health; PWD may provide \$40/month with prescription; time limited	Between \$480 and \$1,000 per year for most; occasionally ranges as high as \$1800
Cost of diagnosis (if required)	\$4,000.000 one time cost
Cost of medical forms	\$25.00 per form per occasion plus cost of the office visit

<b>ITEM</b>	<b>COST ESTIMATE PER INDIVIDUAL TO FAMILY</b>
Assessments (non PWD)	\$1,000.00 per occasion and up
Cost of PWD assessments and paperwork	\$250.00 to \$1,000.00 each re-assessment
Damage deposits (rarely, if ever, recovered; will only be provided once by MCFD; after that, they are deduct from monthly cheque)	\$250.00 per occasion on average
Utility hookups	\$ 150.00 per occasion
Cleaning costs	Highly variable; depending on state, and who does the cleaning; likely about \$150.00 per occasion; can be much higher
Repairs (minor)	\$ 50.00 - \$75.00 not including labour provided by family, per occasion
Repairs (major) – electricians, plumbers, etc.	\$ 250.00 per occasion
Laundry costs (laundromat)	\$ 240.00 per year
Costs of moving, including eviction costs	\$ 300.00 - \$400.00 per occasion
Replacement of damaged, lost, stolen goods/equipment, for individual and others	\$ 750.00 per year
Insurance rider costs	\$ 100.00 per year
Capital costs of furniture (used, from family, etc.)	\$1,000.00 to set up
Capital costs of household goods	\$2,500.00 to set up
Long distance phone calls to/from parents/adult; to other agencies, companies, etc. to deal with events	\$ 600.00 per year
Replacement costs for ID, bus passes, etc.	\$ 200.00 per year
Legal fees (as defendant; as victim); legal aid defense will almost certainly end in jail time	\$3,500.00 per occasion for lawyer, supposes limited court time and offense; serious crime would be much higher and likely out of reach of all families at all times
Fines, tickets (may also have used the name of another leading to fines in their names)	\$ 500.00 per year
Prison visit and support costs (mileage, cost of babysitter in the home, meals, money for prison canteen account, etc.)	\$1,000.00 per year – highly dependent on location of prison, number of visits, etc. Could be much higher
Court costs; transcripts, etc	\$ 250.00 per year
Transportation costs associated with legal situations	\$ 250.00 per year
In-home supervision (bail, probation, house arrest conditions) – allows for 10 hours a week paid time at \$10/hour to allow parent to leave the home	\$ 400.00 per month on average – depending on length of conditions, could be about \$5,000.00 per year cost to keep an adult out of jail (parents do shift work to avoid)
ICBC imposed sanctions	\$ 750 - \$5,000.00 depending on circumstances

ITEM	COST ESTIMATE PER INDIVIDUAL TO FAMILY
Cost of notarized documents	\$ 25.00 per occasion
Handi-dart (door-to-door transportation for disabled adults unable to use bus service for a number of reasons; many with FASD would qualify)	\$ 1,200.00 per year for one return trip daily Monday to Friday
Portion of vehicle costs required to continue to be accessible 24/7; insurance, maintenance, repairs	\$1,200.00 per year – assumes vehicle is paid for
Cost of driving adult to and from to provide supervision/avoid problems – mileage	\$1,200.00 per year
Parking (miscellaneous – meters, lots, etc., for therapy, AA meetings, appts., etc.)	\$ 750.00 per year
Financial “bailouts” (credit cards, finance company loans, lines of credit, bills, fraud, possible drug debts)	Highly variable; highly expensive; usually not done; sometimes has to be
Costs of airfares, bus tickets, hotels, meals, taxis, etc. to reclaim adult kids	\$1,000.00 per year on average
Cost of meals for adult on street	\$ 600.00 per year
Cost of returning belongings from one location to another	\$ 150.00 per year
Costs associated with illness/injury in child requiring parent to attend another city, etc.	\$3,000.00 and up per occasion, depending on location (high cost airfares; short notice; plus hotels and meals)
Cigarettes	\$ 600.00 per year
Recreation passes	\$ 100.00 per year
Entertainment	\$ 500.00 per year
Cost of accessing treatment (finding it, getting a person there, etc.)	\$ 500.00 and up per occasion, depending on lost time from work, travel, location, etc.
Adult vocational services	\$1,000.00 per year adult basic education
Vocational rehabilitation services	\$1,000.00 and up per occasion
Vocational training courses	\$3,000.00 per year and up
Employment supports (special shoes, clothing, tools, etc.)	\$ 500.00 and up depending on job needs; per job placement
Cost of time spent educating employers, providing supports to them, etc.	Dependent on amount of time parent must take to do this
Clothing and shoes (additional); includes cost of having to re-outfit	\$1,000.00 per year
Food	\$1,000.00 per year
Personal care	\$ 250.00 per year

<b>ITEM</b>	<b>COST ESTIMATE PER INDIVIDUAL TO FAMILY</b>
Gifts	\$ 200.00 per year
Support to grandchildren's costs	Usually substantial costs depending on where the child is being raised; likely minimum amount is about \$5,000.00 per year
Replacement of cell phones	\$ 100.00 per occasion
Paid one-to-one worker	\$4,800.00 per year – 5 hours per week at \$20/hour
Respite care	Rarely ever due to lack of funds; would cost in neighbourhood of \$150.00 per day and up

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