Fetal Alcohol Spectrum Disorder

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Learning Objectives

- Understanding of FASD as a disability
- Recognition of the complex needs of individuals with FASD
- Understanding social and behavioral concerns in context
- Learn about current research initiatives
- Learn about what constitutes best practice
- Engage in discussions about FASD informed practice
- Learn about available resources for further learning
Fetal Alcohol Spectrum Disorder

- FASD is a non-diagnostic umbrella term to describe brain damage and a wide range of disabilities caused by maternal alcohol consumption in pregnancy leading to difficulties with cognitive, social, emotional, language and behavioral functioning.
- Often defined as a neurodevelopmental disorder – meaning that neurological function was impaired at early stages of growth (in utero) and damage is permanent.
- First article on FAS was published in 1973 by Dr. David Smith and Dr. Kenneth Lyon Jones.
The Spectrum

- FAS – Fetal Alcohol Syndrome
- PFAS – Partial Fetal Alcohol Syndrome
- ARND – Alcohol Related Neurodevelopmental Disorder
- ARBD – Alcohol Related Birth Defects

- These diagnoses are based on four major diagnostic criteria:
  - Fetal alcohol exposure
  - Growth deficits
  - Neurodevelopmental and behavioral characteristics (CNS damage)
  - Distinctive facial features* - facial features only present in less than 10%
The Impact: Brain Domains Affected by FASD (Primary Disabilities)

- Frontal lobes – controls impulse and judgement, executive functions i.e. time management, planning, judgement, empathy
- Hippocampus – memory, learning, emotion
- Hypothalamus – emotions, appetite, pain, sensation
- Cerebellum – coordination, movement, behavior
- Basal Ganglia – perception of time and spatial memory
- Amigdila – emotional circuitry i.e. fear, anxiety, aggression, social behaviors
Primary Disabilities

- physical and health conditions (e.g., issues with oral palate, kidneys, heart, spine and sensory systems);
- delays in meeting developmental milestones;
- difficulties in memory, comprehension of language (written and oral) and social cues, and cognitive functioning (slow mental processing, difficulty with abstract thinking and reasoning);
- poor fine and gross motor skills;
- poor behaviour regulation;
- trouble maintaining appropriate attention and focus; and
- problems with adaptive skills.
- confabulation (e.g., the individual may make up information to fill in the gaps in their memory or understanding, or in an effort to please others), which is often perceived as lying (Rutman, La BERGE, & Wheway, 2005)
The Impact: Cognitive Challenges & Neurobehaviors

- Behavior is brain based – it isn’t rational, not predictable
- People with FASD often have challenges in the following areas:
  - Thinking patterns
  - Memory/Recall - Seen as ‘not listening’ or not trying
  - Language - Difficulty in both receptive and expressive language learning
  - Learning – retaining information
  - Focus
  - Unstructured time – an opportunity for risk
Defining disability can impact social rights and entitlement to support and care.

The medical vs. social definition of disability presents a quandary in relation to service provision.

Disability is not an illness. Medical diagnosis can inform or severely limit our understanding of disability.

“FASD is for the most part an invisible disability and individuals with FASD struggle in ways most of us can’t even imagine” - Donna Debolt
Understanding FASD as a Disability

- FASD is not always perceived as a disability and these processing/communication difficulties can lead to unrealistic expectations of parents/caregivers and increased frustration and behavioral problems on the part of the individual.

- Without a diagnosis and some understanding of the challenges faced by a child/adults, a confounding and complex series of psychosocial, emotional and behavioral problems can, and often does emerge.

- Children/adults become subsequently identified as non-compliant, manipulative and lacking in motivation while parents and caregivers (foster parents) become increasingly challenged in effectively supporting the child (Dubovsky, 2013).
Those with FASD often do not conform to current standards or guidelines for service eligibility in systems because they are not mentally handicapped (their disability remains hidden), service systems treat individuals with FASD as entirely competent with the capacity to understand, plan and take responsibility for their actions.

Average IQ for people with FASD is 75-85, with full range between 20-140 (intellectual mental handicap is less than 70).

- BUT almost all those with FASD have Adaptive Quotient (AQ) less than 70.
- AQ measures one’s ability to function day to day without supports in the areas of: communication, socialization, daily living skills, time management, employment, critical thinking, judgement, etc.
- AQ less than 70 is considered adaptive mental handicap.
Assessments and Diagnostics

- There is no bio-marker, lab test or scanning to diagnose FASD.
- Diagnosis requires a comprehensive medical and psychosocial assessment by a team of professionals, generally known as an FASD diagnostic team, and confirmation of prenatal alcohol exposure is required.
- However, in the absence of this information it does not mean that an individual who is suspected to have an FASD should not be assessed.
- Assessment and diagnosis of FASD is most accurate when done between ages of 2-11.
Assessments and Diagnostics

FASD diagnosis involves the following (Public Health Agency of Canada, 2011):

- **physical examination**: involves appropriate measurements of growth, assessment of findings, and documentation of anomalies;

- **dysmorphology assessment**: can identify specific facial features related to prenatal alcohol exposure;

- **neurobehavioural assessment**: involves and evaluation of the hard and soft neurological signs, brain structure, cognition, communication, academic achievement, memory, executive functioning and abstract reasoning, and attention deficit/hyperactivity; and

- **confirmation of prenatal alcohol exposure or alcohol consumption by the mother during the pregnancy**: can be obtained through a direct interview with the mother or other sources (e.g., reliable clinical observation, reports by a reliable sources, or medical records).
Diagnostic Centers in Calgary

- MediGene Services, FAS Diagnostic Clinic
- Renfrew FASD Assessment and Diagnostic Clinic
- Alberta Children’s Hospital Fetal Alcohol Spectrum Disorder Diagnostic Clinic
Assessment and Diagnosis: Challenges

- Not currently a valid screening test (Canadian Association of Pediatrics is working on one)
- Children with this disability are not necessarily easily recognized until they reach school age and this is one of the reasons FASD is known as an invisible disability.
- Diagnosis of FASD becomes more difficult after early childhood and services for assessment and diagnosis in adults is limited.
- Hourly rate of assessments is $150/hour and can take up to 10 hours to complete.
Assessment and Diagnosis: Benefits

- Shifts understanding to brain damage
- Helps the individual to receive appropriate services and makes them eligible for certain services (e.g., PDD);
- Provides better self-awareness and understanding by family members and friends;
- Allows service providers to make accommodations in services and supports; and
- Aids communication among clinicians, caregivers, educators, and families
- “They know that they struggle, but in the absence of a diagnosis they do not understand, or know why” – Public Health Agency Canada
Social Determinants of Health & Post-natal Environment

- SDH considers social and economic factors such as income, wealth distribution (poverty), employment, education, housing (living conditions)

- The environment a person lives in directly impacts their health and well being (e.g. abuse, neglect, DV, multiple placements, ingoing parental substance abuse, etc..)

- For an individual with FASD, supports are required that help mediate challenges related often to social/behavioral/learning challenges
Secondary Conditions

- Mental health problems
- Disrupted school experience
- Conflict with the law
- Inappropriate sexual behavior
- Alcohol and drug use problems
- Needing dependent living situations
- Problems with employment
- Risk of victimization
FASD Across the Lifespan

- Infancy – sensory integration problems
- Toddler – social cognitive problems, communication and social concerns
- School age – issues with learning emerge
- Adolescence and transition to adulthood
  - MH concerns
  - Physical health concerns
  - Social/emotional concerns
  - Financial concerns
Interplay between FASD and Risk Factors

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<tr>
<th>FASD Primary Effects</th>
<th>Environmental</th>
<th>Psychosocial</th>
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<tr>
<td>• Poor impulse control</td>
<td>• Poverty</td>
<td>• Boredom; Loneliness</td>
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<td>• Poor judgement</td>
<td>• Homelessness</td>
<td>• Hopelessness; Low-self esteem</td>
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<td>• Poor understanding of</td>
<td>• Decreased cultural connection</td>
<td>• “Normalization” of abuse/violence/vi</td>
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<td>cause and effect</td>
<td>• Few healthy role models</td>
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<td>• Poor receptive language</td>
<td>• Experience of abuse/exploitation</td>
<td>• High stress/anxiety/depression</td>
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Co- and Tri-Morbidity

- Popova, Lange, Rehm (2012) identified more than 300 diseases and conditions associated with FASD.
- Health problems related to: aberrant immune responses, abnormally high pain tolerances, chronic infections, seizures and additional physical alcohol related birth defects.
- Up to 94% of people with diagnosis of FASD have at least one MH diagnosis in adulthood. Most common include: attention deficit disorder, major depressive disorder, psychotic disorders, autism, bipolar disorder, personality disorders, substance use disorders, schizophrenia, conduct disorder, reactive attachment disorder).
- “Alphabet soup” → people with unrecognized FASD go from professional to professional seeking solutions to serious behaviors… each diagnosis only captures part of the problem.
FASD and the Correctional System

- Ontario JHS research suggests the rate of FASD is 10x higher inside Canadian prisons than the general population
- Public Health Agency Canada suggests 60% of people diagnosed with FASD have had difficulties with the law
- Consequences of imprisonment for people with cognitive disabilities:
  - entrenchment within a culture of criminality, as individuals with cognitive disabilities often want to be accepted by their peer group;
  - a vulnerability to be the victims of violence or mistreatment in the prison environment; and
  - post-release re-adjustment problems, as individuals with cognitive disabilities often have impaired adaptive skills
FASD and Child Welfare

- 6% children in care have FAS; 17% had a condition along the spectrum of FASD
- 34% of children in care with disabilities have FASD
- Cost to support a child with FASD in care is $15,000 more
- Lack of understanding of FASD among caregivers within child welfare system → multiple placements and disruptions
- Average child with FASD will obtain grade 9 education
Parents with FASD

- Research is limited – what does exist suggests:
  - 30% were diagnosed before they became parents
  - Child apprehension rates 36%
  - Child abandonment rates by fathers 45%
  - 40% mothers drank during pregnancy
  - 17% children born to mothers with FASD were diagnosed FAS or PFAS
  - Additional 13% suspected FAS
Alcohol Consumption During Pregnancy

- FASD is a diagnosis that in theory is preventable but in practice, this is a difficult assumption without placing it in a context of women’s health.
- Women who give birth to children with an FASD are known to have histories of trauma and face many challenges in their lives.
- To think about prevention, we have to think about the cause.
- The need exists to first examine the cause – which is not solely alcohol use during pregnancy – the roots are much deeper.
- Looking at FASD from a women’s health perspective a portrait emerges that generally includes a history of trauma, abuse and exposure to alcohol within their family (Badry, 2008).
FASD and Women

- “I have never met a mother who drank during pregnancy because she wanted to hurt her child or because she didn’t care.” Dr. Ann Streissguth, 1997

- A profile of birth mothers suggests they are a marginalized population**

Barriers to accessing treatment cited by mothers:

- Shame (66%)
- Fear of losing children (62%)
- Fear of prejudicial treatment on the basis of their motherhood status (60%)
FASD in Alberta

- Estimated 36,000 Albertans living with FASD
- 450 babies born each year with FASD
- Annual cost associated with FASD in AB (inclusive of health, social, education and corrections) is $927.5 million
- Alberta has responded to FASD by creating a Ten Year Strategic Plan that began in 2006
- This plan is a reflection of recognition of FASD as a serious public health issue
- This plan serves as a foundation for building policy in areas such as diagnostic clinics, FASD networks and various research projects related to FASD
FASD and Homelessness

Consequences of FASD create the risk factors for homelessness:

- Low educational attainment, family stress/breakdown, challenges with keeping a job, low social skills
- High risk for abuse and exploitation
- Substance use
- Mental health challenges
- Involvement with criminal justice system and child welfare system
“Many adults with FASD are difficult to house. They do not follow the rules because they do not understand them or 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 or change behavior as a result of them. This is the consequence of brain damage, not deliberate, thought out or planned”.

The effects of FASD can impact the person’s ability to maintain their own accommodation.

- a vulnerability to be easily influenced or taken advantage of by others;
- a lack of cleanliness
- difficulty in comprehending and following rules or instructions;
- difficulties with budgeting and management of money;
- difficulties with planning;
- experiences of exclusion from services or agencies.
The Challenge

- Limited understanding of individuals with FASD exist within the homeless population.
- Lack of understanding on effective interventions for homeless persons with FASD – often leading to labels of “non-compliant”
- Mental health needs, addictions, and housing need to be effectively addressed.
- Assessing the prevalence of FASD in the homeless community.
Misinterpretation of Behaviors

- Due to their disability, the behaviors of adults with FASD may make them difficult to work with.
- Experience challenges following through with supports/plans put in place for them – they may reject services because they are unable to comprehend what is being asked of them or because they fail to see the benefits of their participation.
- This can lead to individual being labelled “non-compliant”, “challenging” or “hard to house” because their disability does not allow full participation in the process.
- The often misunderstood needs of adults with FASD can lead to inaccurate assumptions of client motives.
- These behaviors, if not well understood, often lead to a client becoming blamed for such problems and this further disenfranchises individuals from supports that could be helpful if framed from an FASD informed perspective.
Biological vs. Functional Age

Common Developmental Profile for an 18 year old adolescent with FASD

- Physical Maturity
- Reading Ability
- Money & Time Concepts
- Understanding Language
- Daily Living Skills
- Social Skills
- Emotional Maturity

Functional Age in Years

*SAMHSA, 2005
Best Practices & FASD Supports

- Best Practice means, “an intervention, method or technique that has consistently been proven effective through the most rigorous scientific research (especially conducted by independent researchers) and which has been replicated across several cases or examples. To be a ‘best practice’, an intervention must be able to show that it produces better results than other approaches and that is a practice that can potentially be adapted with success in other contexts and/or scaled up to a systems-wide approach. In other words, there is a sufficient body of evidence that allows us to confidently say that the described practice is a generalizable example of something that works”
Promising Practices

- Several models for housing individuals with FASD - but limited evidence on their effectiveness
- Lakeland Center suggests effectiveness is most evident when:
  - There is an understanding of FASD as a disability
  - Presence of strong community
  - Removal of barriers in eligibility
- There is a need for flexible housing options that do not require the individual to be responsible for all aspects of the situation
- Address housing and supports from a systematic, planned, multi-pronged approach
- Housing and support needs will depend on degree of CNS damage and presence of secondary disabilities
Contradictory Paradigms

- “A basic understanding of FASD exists, but a model for understanding the intricacies and implications of this diagnosis on day-to-day living is not coherent in practice” – Government of Canada
- Treatment programs based on cognitive abilities are bound to fail. It is not the individual with FASD is failing the program, it is the program is not working for the individual
- Challenges with memory re-call and standard assessments need to be modified (e.g. SPDAT)
- Standard interventions such as MI, relapses prevention, CBT, psychoeducation, or group therapy are likely to be ineffective if they are too cognitively demanding
FASD Informed Interventions and Supports

- FASD informed care means that social and behavioral concerns are reframed – each problem an individual needs is reviewed and examined from an environmental perspective.
- Re-frame behavior as brain based – not intentional.
- Need strategies that provide well defined goals, repetition of materials, concrete explanations, continual reinforcement of behaviors and aids for memory enhancement.

- Once they grow to understand the neurological impairment and its effects on behaviours, professionals and caregivers experience a significant shift in the way they perceive individuals affected by FASD. Feelings of frustration and anger evolve into understanding, increased patience and acceptance (Malbin, 2002).
FASD Informed Interventions and Supports: Practice Based Strategies

- Use service modalities that are not cognitively demanding
- Set well defined goals for all services
- Repeat basic concepts and instructions
- Provide concrete explanations of action to be taken
- Offer continual behavioral reinforcements
- Use memory enhancement approaches
- Structured skill learning
Effective Strategies for Support

- Structure
- Routines
- Consistency
- Congruency across environments if possible
- Get everyone at the same table
- Harmonize responses in relation to the individual
- Promote consistency across environments
- Look for concerns early
- Provide structure, routine
- Use tools such as charts, calendars – use these consistently – make it visual – engagement
Effective Strategies Cont’d

- Thinking patterns - Use concrete thinking – don’t give too many instructions at once
- Memory/Recall - Seen as ‘not listening’ or not trying
- Language - Difficulty in both receptive and expressive language learning
- Learning – retaining information – repeat things often
- Focus – attention to task – remove distractions
- Unstructured time – an opportunity for risk – create structure and routine to mediate these challenges

- Recognizing what triggers behaviors is important
- Practice shift – avoid triggers, maintain routine, structure and consistency
Guidelines for Working with Someone who has FASD

- Keep it simple.
- Slow down, allow time to adjust to new activities/environments.
- Allow for lots of breaks.
- Focus on strengths.
- Connect individual with a support person.
- Try different (ways), not try harder.
- Communicate using concrete language and examples.
- Ask questions to check for understanding.
- Alter the environment.
- Be organized.
- Have consistent routines.
- Be clear with expectations and be consistent.
- Remember the individual’s developmental age.
Strengths based approach

- Strengths based is a case management approach that has developed in consideration of client resilience and ability to access resources.
- Insists that we looks at individuals, families and communities differently
- **Language of strengths based approach** ("ability, talents, competency") demand that we stand up against words like “incompetency, non-compliant, diagnosed, dysfunctional”
Pregnancy Pathways - Edmonton

- Choice driven/self-determining
- Community-based
- Culturally safe
- Flexible
- Harm reduction oriented
- Health promoting
- Recovery focused
- Relational

- Respectful
- Strengths based
- Supportive of parenting
- Trauma informed
- Use of disability lens
- Women-centered
- Child safety and protection
Resources!

- Canada FASD Research Network
  - [http://www.canfasd.ca](http://www.canfasd.ca)
- Alberta FASD Cross Ministry Committee
  - [www.fasd.alberta.ca](http://www.fasd.alberta.ca)
- Caregiver Curriculum on FASD
  - [www.fasdchildwelfare.ca](http://www.fasdchildwelfare.ca)
Assessment and Diagnosis of FASD Among Adults

A National and International Systematic Review
Mission:
To promote and protect the health of Canadians through leadership, partnership, innovation and action in public health.

— Public Health Agency of Canada
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Executive summary

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

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

\(^1\) [www.ccsa.ca/Eng/KnowledgeCentre/OurDatabases/FASD/Pages/default.aspx](http://www.ccsa.ca/Eng/KnowledgeCentre/OurDatabases/FASD/Pages/default.aspx)
strategically directed research initiatives related to Indian and Northern Affairs Canada, Justice Canada and Youth Justice Policy, and Public Safety Canada. It is recognized that this is not an exhaustive list as many awareness, training and intervention initiatives have evolved over the years.

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

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

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

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

1. Conduct a systematic search and assembly of Canadian and select international, empirical and qualitative literature and data on the assessment and diagnosis of adults for the impact of in utero exposure to alcohol.

2. Create a synthesis and critical review of the information obtained, including the identification of strengths, limitations and gaps.

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

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

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

More recently, Sullivan (2008) focused on underlying vulnerabilities and problems in life adaptations, including “poor parental role modeling, disturbed development of trust and identity, patterns of avoidant coping behaviour, dysfunctional adolescent and adult relationships, and economic disadvantage” (p. 226). These concerns are realities for adults with the disorder and indeed pose challenges as intervention aimed at ameliorating these concerns is time-intensive and costly. A small literature is beginning to appear that focuses on the quality of life of individuals living with FASD, which may provide a fuller picture of what it means to live with FASD and how we can improve the quality of life for these children, adolescents and adults (Grant, Huggins, Connor & Streissguth, 2005; Stade, Stevens, Ungar, Beyene & Koren, 2006).
Since FASD has been identified as a health concern in Canada and other countries, the need to address the issue across the lifespan falls within the practice framework of health, social services and the community. Although FASD does not fit neatly into the adult world of developmental disability due to many of the inherent social problems and neurobehavioural problems associated with this diagnosis, consultation in relation to working with systems and supports for adults with disabilities can inform the development of service models.

**Conclusions and Implications**

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

Canada, however, has demonstrated remarkable leadership in responding to the issue of FASD. The establishment of clinics for children should lead to the establishment of clinics for adults that are publicly funded in order to support individuals who do not have the resources to obtain a diagnosis on a fee-for-service basis. The potential exists for the costs of screening and assessment to put a fiscal strain on community-based agencies. However, publicly funded diagnosis is not consistently applied on a federal basis and discrepancies in the delivery of this service both in policy and practice should be addressed.
Referrals for adults would have to be restructured from the processes for children and strong screening protocols established for referrals to adult clinics. The potential for self-referral by adults is likely, as many may not be connected to agencies that might facilitate a screening/diagnostic referral. Following already established referral/screening/diagnostic protocols for children with some adjustments for adults would save time and fiscal resources in the development of adult clinics. As well, consultation with already established adult diagnostic resources would be useful to gain knowledge about their procedures and protocols.

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

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

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

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

Chudley, Kilgour, Cranston and Edwards (2007) described the wide range of features characterized by the various diagnoses within the spectrum of FASD diagnoses as those diagnosed with FAS at one end and those with behavioural and cognitive deficits who may have minimal or no physical characteristics but who have sustained brain injury due to in utero alcohol exposure at the other end. The diagnostic terms encompassed by FASD as per the published recommendations of the U.S. Institute of Medicine in 1996 include FAS (Jones, Smith, Ulleland & Streissguth, 1973), Partial FAS (pFAS), which was previously referred to in the literature as Fetal Alcohol Effects (FAE) (Streissguth et al., 1991; Streissguth, Barr, Kogan & Bookstein, 1997) and a more recent addition to the terminology – Alcohol Related Neurodevelopmental Disorder (ARND) (Sampson et al., 1997; Stratton, Howe & Battaglia, 1996) and Alcohol-Related Birth Defects (ARBD). It was recommended by medical experts Aase, Jones and Clarren (1995) that FAE not be used due to negative interpretations and misconceptions related to this term, particularly regarding the issue that fetal alcohol exposure was the sole cause of problems for the individual. The 4-Digit Diagnostic Code does not use ARND and indicates that “static encephalopathy” is a term that is used to reflect more severe neurodevelopmental problems, while the term “neurobehavioural disorder” reflects a milder problem (Astley, 2006).
1.1 Project Scope

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

1. **Conduct a systematic search and assembly of Canadian and select international, empirical and qualitative literature and data on the assessment and diagnosis of adults for the impact of in utero exposure to alcohol.**

2. **Create a synthesis and critical review of the information obtained, including the identification of strengths, limitations and gaps.**

3. **Prepare recommendations of next steps for areas of further research.**

1.2 Adult Diagnosis in Context

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

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

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

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

The concept of FAS had its origins in the early 1960s. An article entitled *The children of alcoholic mothers, observed anomalies*, discussion of 127 cases, was published in the French Archives of Paediatrics by pediatrician, Dr. Paul Lemoine in 1968. Lemoine (2003) stated:

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

The second study, by me [Lemoine], started with no pre-conceived thoughts about alcoholism. It was while researching the cause of a strange dystrophy seen in certain children that I discovered alcoholism in their mothers. Around 1960, I was struck by the existence of a yet unknown syndrome among these children... the children all looked as if they were siblings. I was comparing two of these children looking for an answer, and while talking to the staff as I always did, one of them responsible for the two children indicated to me that both of their mothers were heavily alcohol dependent... All of the children marked by this syndrome had alcoholic mothers. (Lemoine, 2003, p. 2)
Lemoine described a methodology in which he both physically observed children in his practice as a pediatrician and subsequently did file reviews of each case. However, the genesis of the terminology FAS did not spring from Lemoine’s work in 1960 as one would expect. Lemoine (2003) had used the term “alcoholic fetopathies,” which he indicated meant the same as the North American term “FAS.”

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

Eight unrelated children of three different ethnic groups, all born to mothers who were chronic alcoholics, have a similar pattern of craniofacial, limb, and cardiovascular defects associated with prenatal-onset growth deficiency and developmental delay. This seems to be the first reported association between maternal alcoholism and aberrant morphogenesis in the offspring.... Eight children born of alcoholic mothers were brought together and evaluated at the same time by the same observers (K.J. and D.W.S.). Four of these children were recognised as having a similar pattern of altered growth and morphogenesis. Thereafter, two other children were ascertained by the abnormal features identified in the first four patients, while the remaining two affected children were ascertained because their mothers were chronically alcoholic.... All drank excessively throughout the pregnancy, the mothers of patients 1 and 7 to the extent that they were in hospital with delirium tremens. Patient 3 was born while her mother was in an alcoholic stupor. None of the mothers was known to be addicted to any other drug. (Jones, Smith, Ulleland & Streissguth, 1973, pp. 1267–1271)

Streissguth (1994), in her review of the first decade of research into FAS, highlighted the international nature of the studies citing Lemoine, Harousseau, Borteyru and Menuet in 1968 and Dehaene et al. in 1977 emerging from France; German contributions by Majewski et al. in 1976; from Sweden the research by Olegard et al. in 1979; and research surfacing from the United States by Jones, Smith, Ulleland and Streissguth (1973). Research across the intervening decades, although dominated by North America, has continued to arouse interests from other countries (e.g. Riley et al., 2003 presented six international perspectives on the neurobehavioural consequences of fetal alcohol exposure in South Africa, the United States, Russia and Finland). Another indicator of international research is the studies comparing findings from multiple countries, such as those of Peardon, Fremantle, Bower and Elliott (2008) who sent questionnaires to diagnostic clinics in Canada, the United States, Chile, South Africa, Italy and the United Kingdom; and Moore et al. (2007), who included in their sample 276
subjects from three international sites (i.e. South Africa, Finland and the United States). A report on the proceedings of a workshop held in Japan in 2000 acknowledges research contributions from the United States, South Africa, Japan, Russia and Germany (Warren et al., 2001).

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

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

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

“In FAS, the physical features are only the markers for the CNS deficits.... Although the physical features associated with FAS may change in adolescence, the CNS problems continue, often with more severe repercussions than those experienced in early childhood” (p. 75). Adaptive living deficits resulting from CNS deficits meant that those with IQs in the low normal range seemed “headed for trouble in the community” (p. 76). This finding has been supported by other research studies (e.g. Clark, Minnes, Lutke & Ouellette-Kuntz, 2008; Dyer, Alberts & Neimann, 1997; Grant, Huggins, Connor & Streissguth, 2005; Kerns, Don, Mateer & Streissguth, 1997) as well as the practice literature.
Knowledge about FASD has grown and evolved with each passing decade. The 1990s saw the emergence of a new phase of diagnostic development. There appeared to be two different schools of thought in the United States in terms of diagnosis based on standards set by the U.S. Institute of Medicine (Stratton, Howe & Battaglia, 1996) and the 4-Digit Diagnostic Code (Astley & Clarren, 1999). Diagnosis relies heavily on classification systems, which provide a portrait of the characteristics that constitute a particular condition or disease. A Canadian model for diagnosis has drawn on both the U.S. Institute of Medicine (1996, as cited in Hoyme et al., 2005) literature and the Diagnostic Prevention Network 4-Digit Diagnostic Code developed by Astley & Clarren (1999). The Canadian guidelines retained the standards of the 4-Digit Diagnostic Code and the spectrum terminology of FASD from the U.S. Institute of Medicine (IOM) model. The Canadian guidelines for a diagnosis of FAS include: “evidence of prenatal growth impairment [related to weight and height], simultaneous presentation of 3 [particular] facial features, evidence of impairment in 3 [particular] ... central nervous domains [and] confirmed (or unconfirmed) maternal alcohol exposure” (Chudley et al., 2005, pp. s11–s12).

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

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

Hutson (2006) estimated that

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

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

Concerns about alcohol use and pregnancy have been raised as emerging concerns in other countries (e.g. alcohol use during pregnancy in Russia is a serious problem, which the West recently became more aware of, due to international adoptions of children from orphanages into Canada, the United States and other countries). One study by Miller et al. (2006) examined an orphanage in Russia, and considered the use of alcohol within this society. “Alcohol use in Russia is staggering; the annual consumption is among the highest in the world” (p. 532). Miller and colleagues estimated that 58% of children (n = 234) in a particular orphanage showed visible symptomology of “prenatal alcohol exposure” (p. 531). This prevalence rate was determined through a multi-level examination that included file reviews, growth measurements, and an assessment of children using the phenotype or facial screening assessment (Astley & Clarren, 1996). Developmental assessments were reviewed for 112 children, of whom “21 (19%) had mild delays, 45 (40%) had moderate delays and 12 (11%) had severe delays…. More than 70% of children with high phenotypic scores were categorized as moderate or severe delay” (Miller et al., 2006, p. 536). There are multiple conditions in institutions that contribute to the developmental problems of children living in congregate care where there are limited opportunities for stimulation.

![Figure 1](image)

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

- **Severe delays**: 11%
- **Mild delays**: 19%
- **Moderate delays**: 40%
The diagnosis of adults is an evolving field and is in its early origins. At present, Sullivan (2008), specifically in reference to adults, has suggested that because “diagnosis still rests upon retrospective information, and often is not made until the life trajectory is firmly set, these patients may be referred for psychiatric evaluation from a wide range of settings” (p. 215). Concerns related to mental health are substantial, and Sullivan (2008) focused on the underlying vulnerabilities and problems in life adaptations, including “poor parental role modeling, disturbed development of trust and identity, patterns of avoidant coping behaviour, dysfunctional adolescents and adult relationships, and economic disadvantage” (p. 226). Major trend(s) in the new millennium in FASD research must include the evolution of research agendas that focus on post-diagnosis supportive practice and casework for adults. Diagnosis needs to be followed with a response that includes developing a support system and case planning tailored to the specific needs of the individual.

1.3 Need for Adult Assessment and Diagnosis

There are several reasons why there is a need to address adult diagnosis and assessment. First, FASD has been identified as a major public health concern in Canada and other international jurisdictions (Moore et al., 2007; Peadon, Fremantle, Bower & Elliott, 2008; Warren et al., 2001). FASD is recognized as a disability that is expensive to manage, and these concerns are magnified because the condition is preventable through abstention from alcohol during pregnancy. This has prompted many Canadian provinces to make, or to engage in the process of making strategic plans for preventing FASD, as well as to identify and intervene with children, adolescents and adults diagnosed with one or more of the multiple conditions associated with FASD. In part, the substantial response to the needs of children for diagnosis and treatment of FASD has paved the path in terms of recognition that similar services are required for many adults who are undiagnosed and demonstrating struggles associated with FASD. As these strategic provincial plans are enacted and public awareness raised, it can be expected that more adult referrals will be made to the diagnostic clinics and programs that exist or that will be established as part of the resources to implement these plans.
Second, epidemiological estimates for FASD within the general population have been established, having been extrapolated from clinical and research data. However, there are no estimates of how many children are actually diagnosed with FAS or its related disorders in Canada, or how many children grow to adolescence or adulthood without an appropriate diagnosis (Clarren & Lutke, 2008). We do know, however, that adults are presenting themselves at diagnostic clinics or programs with suspected FASD but have operated below the diagnostic radar to date. Clarren and Lutke (2008), in a 2006 survey, identified a total of 27 programs in Western and Northern Canada engaged in FASD diagnostic activity. They reported an astounding rate (67%), of those referred to clinics, receiving some form of FASD diagnosis. This research identified the concerns about the lack of prevalence rates for Canada, while highlighting the need for ongoing diagnosis, research and diagnostic consistency.

This highlights a third need for adult assessment and diagnosis information – the inconsistency of diagnosis in relation to adults. There are many adults who are never diagnosed, misdiagnosed and even self-diagnosed as having an FASD. Standard practice in relation to diagnosis for adults is not well established in Canada or elsewhere. The potential exists for the successful strategies used in the diagnosis of children and adolescents to be applied to adults, as evidenced by the strategies of the few existing clinics that diagnose adults in Canada (Clarren & Lutke, 2008). It is also important to understand and codify the differences that should be taken into account when dealing with an adult population not previously diagnosed. With greater clarity around diagnosis, efforts could be initiated to have FASD recognized as a disabling condition that requires funding by governments, designated for assessment and support services. Perhaps this will lead to services related to diagnosis and assessment being covered by provincial health care.

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

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

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

The Asante Centre also recognizes that adults with an FASD diagnosis may then have access to services that are better able to meet their needs, and could help others know how best to offer support. The Lakeland FASD Centre located in Cold Lake, Alberta, which covers a vast rural area, began adult diagnosis in 2000 (McFarlane & Rajani, 2007). Key issues for the 22 adults diagnosed through this clinic between 2001 and 2004 were employment, physical health, mental health, justice issues, independent living, finances and addictions. The relevance of diagnosis to these adults is that supports can be delivered through individual planning in order to assist them in negotiating these challenges while living in their communities.

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

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

2.1 Approach and Methodology

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

2.2 Peer-Reviewed Literature: Search and Review Strategies

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

<table>
<thead>
<tr>
<th>Database Searched</th>
<th>Terminology in Abstract</th>
<th>Articles Selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ovid with all search engines, including CAB Abs, Global Health, ERIC, EMBASE, CDSR, ACP Journal Club, DARE, CCTR, CLCMR, CLHTA, CLEED, AMED, HealthSTAR, PsycINFO, Your Journals@Ovid, Ageline, Journals@Ovid, Ovid MEDLINE(R)</td>
<td>FASD or fetal alcohol spectrum or fetal alcohol syndrome AND adult</td>
<td>36</td>
</tr>
<tr>
<td>Ovid Healthstar &lt;1966 to August 2008&gt;</td>
<td>Fetal alcohol or FASD or fetal alcohol syndrome or fetal alcohol AND adult</td>
<td>57</td>
</tr>
<tr>
<td>Ovid MEDLINE(R) &lt;1950 to September Week 3 2008&gt;</td>
<td>FASD or fetal alcohol or foetal alcohol spectrum or fetal alcohol syndrome or FAS AND adult</td>
<td>37</td>
</tr>
<tr>
<td>Pub Med</td>
<td>FASD or fetal alcohol AND adult</td>
<td>19</td>
</tr>
<tr>
<td>All University of Calgary databases</td>
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<td>8</td>
</tr>
<tr>
<td>Faculty of 1000 Medicine</td>
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<td>0</td>
</tr>
<tr>
<td>ISI Web of Knowledge</td>
<td>fetal alcohol AND adult NOT rat</td>
<td>3</td>
</tr>
</tbody>
</table>
Key criteria were used in the decision tree for selecting articles for inclusion/exclusion in the literature review. We located each document and reviewed the abstract or entire document if there was no abstract to determine if the document met our inclusion criteria. The following describes the inclusion/exclusion criteria.

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

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

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

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

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

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

<table>
<thead>
<tr>
<th>Website</th>
<th>Website URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Organization on Fetal Alcohol Syndrome</td>
<td><a href="http://nofas.org">http://nofas.org</a></td>
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<tr>
<td>University of Washington: Fetal Alcohol and Drug Unit</td>
<td><a href="http://depts.washington.edu/~fada">http://depts.washington.edu/~fada</a></td>
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<tr>
<td>University of Washington: Fetal Alcohol Syndrome Diagnostic and Prevention Network</td>
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</tr>
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<td>FASlink: Fetal Alcohol Disorders Society – home page</td>
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</tr>
<tr>
<td>Al-Anon/Alateen</td>
<td><a href="http://www.alateen.org">http://www.alateen.org</a></td>
</tr>
<tr>
<td>Calgary Fetal Alcohol Network</td>
<td><a href="http://www.calgaryfasd.com">http://www.calgaryfasd.com</a></td>
</tr>
<tr>
<td>Renfrew Educational Services: Fetal Alcohol Spectrum Disorders Diagnosis and Intervention Services (FASD)</td>
<td><a href="http://www.renfreweducation.org/desktopdefault.aspx?tab1d=35">http://www.renfreweducation.org/desktopdefault.aspx?tab1d=35</a></td>
</tr>
<tr>
<td>FAS Bookshelf Inc.: FAS Links</td>
<td><a href="http://www.fasbookshelf.com/links.html">http://www.fasbookshelf.com/links.html</a></td>
</tr>
<tr>
<td>FASCETS – Diane Malbin’s work can be adapted for use in adult diagnosis according to another member of the NAT.</td>
<td><a href="http://www.fascets.org">http://www.fascets.org</a></td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome/Fetal Alcohol Effects Outreach Project</td>
<td><a href="http://www.faseout.ca/eng/home.htm">http://www.faseout.ca/eng/home.htm</a></td>
</tr>
<tr>
<td>Canadian Centre on Substance Abuse</td>
<td><a href="http://www.ccsa.ca">http://www.ccsa.ca</a></td>
</tr>
<tr>
<td>FASD Community Circle in Victoria. There is a three-year project taking place in relation to adult diagnosis and it has several instruments developed. The contact is <a href="mailto:davidgerry@shaw.ca">davidgerry@shaw.ca</a>.</td>
<td><a href="http://www.fasdconnections.ca">http://www.fasdconnections.ca</a></td>
</tr>
</tbody>
</table>
Information on FAS/FASD is developed by practitioners or community groups, so it was important to review websites for relevant unpublished resources, including tools, checklists, organizational descriptions, program development, workshops and descriptive experiences from adults living with or caring for an adult living with FAS/FASD. Searches were performed on Google with the following terms:

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

### 2.4 Processing the Literature

The resulting literature included over 100 peer-reviewed journal articles and practice-related documents. Each document was inventoried to categorize the information for further analysis. A concept-centric approach was used to review and classify the studies collected. This involved the creation of a concept matrix to review, synthesize and critically analyze the literature and data located on adult diagnosis and assessment. Once the concept matrix was complete, documents could be grouped, summarized and critically analyzed.

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

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

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

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

One of the clinical practice issues driving the diagnosis of adults is related to child welfare interventions. The Lakeland Centre for FASD, for example, found that 60% of its adult clients who had been diagnosed with some form of FASD had children, and many of those children (40%) were living in the care of others (McFarlane, 2008). The high incidence of children in care was also mentioned by Dubovsky (2008) when he referred to an unspecified study where “over 80% of children and adolescents with an FASD were in foster or adoptive homes” (Slide #22), and by Hutson (2006), who cited a report from the Child Welfare League of Canada in 2003 that estimates that “50% of children in care in Alberta have FAS” (p. 2). So, when children are suspected to have or diagnosed with an FASD, the concern for the family rises because the reality is that parents themselves may have an FASD. In such cases, the availability of a diagnostic clinic, which is accessible and prepared to do adult assessments, would be very helpful in order to assess/diagnose these adults in a consistent and coherent fashion. Such clinics could be instrumental in establishing support plans that recognize the unique needs of such individuals and families. When authorities, such as child protection practitioners, have become engaged in the lives of children and families where concerns of substance misuse is an issue and referral for adults is required, the assessment is now usually done on a fee-for-service basis.
The diagnostic process set out in the Canadian guidelines provides the overarching context for diagnosis of FAS and its related disorders in Canada (Chudley et al., 2005). These guidelines seek to harmonize those created by the U.S. Institute for Medicine (1996, as cited in Hoyme et al., 2005) and the 4-Digit Diagnostic Code (Astley & Clarren, 2004). The use of these diagnostic tools requires testing in multiple domains by specialized professionals. The first step in this process is potential case-identification and referral to a specialized assessment team.

3.1 Screening and Referral Processes and Procedures

Identification and referral are the first steps in the diagnostic process. Referral should be initiated at the point when a professional begins to suspect an alcohol-related disorder may be involved. This most often occurs when adults present with problems whose symptoms may be representative of FAS/FASD. The National Task Force on FAS/FAE et al. (2004) in its document, Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis, suggested that the referral process demands a “thorough knowledge of the physical and neurodevelopmental domains affected in individuals with FAS, as well as characteristics that could trigger a referral” (see Bertrand, Floyd & Weber, 2005, p. 7). The Centers for Disease Control and Prevention’s (2005) guidelines contain a section on identifying and referring individuals with FAS, as do the Canadian guidelines (Chudley et al., 2005). These guidelines were developed with the idea that when in doubt, it was preferable to refer for full evaluation by a multidisciplinary team with experience in evaluating fetal alcohol exposure and its associated problems. However, in many instances, a multidisciplinary team is not available and the primary care physician may be called upon to complete the diagnosis. Referral to a multidisciplinary team (e.g. dysmorphologist, clinical geneticist, mental health professional and social worker) is preferable for two reasons. First, it is often necessary for diagnosis because the growth, central nervous system (CNS) deficits and facial features of FASD can overlap other syndromes and disorders, making a differential diagnosis difficult for those less trained to assess these characteristics. Also, even for those who clearly meet diagnostic criteria, referral to a specialized team allows for a complete assessment and the development of an individualized management plan. This plan is essential if appropriate services and treatment are to be provided.

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

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

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

1. In utero alcohol exposure is known

2. In utero alcohol exposure not known but social and family history indicates:
   a. Parent or caregiver reports that a child has or might have FAS
   b. Premature maternal death related to alcohol use
   c. Focus on children living with an alcoholic parent
   d. Current or previous abuse or neglect
   e. Current or previous involvement with child PSAs
   f. History of transient caregiving situations
   g. Been in foster or adoptive care (including kinship care)

3. In utero alcohol exposure not known but physical characteristics are present in some combination:
   a. facial features
   b. growth deficits
   c. CNS abnormalities

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

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

Goh and colleagues (2008) critically reviewed and evaluated the published literature and practice methods for screening suspected cases of FASD according to their sensitivity, specificity, and positive or negative predictive value. They reviewed seven tools suitable for screening children and adolescents: 1 meconium screening (fatty acid ethyl esters in neonatal meconium); 2 youth-justice screening tool (Asante Centre probation officer screening and referral form); 3 modified Child Behaviour Checklist; 4 facial dysmorphology; 5 maternal history of substance abuse; 6 The Clinic for Alcohol and Drug Exposed Children intake procedure; and 7 the Medicine Wheel. Based on assessments of ease of use, accessibility, cost, expertise, cultural appropriateness, factors to facilitate implementation and barriers to implementation, five of the seven screening tools were assessed as facilitating diagnosis of FASD in different populations. The chosen screening tools were the meconium screening; the Asante Centre probation officer screening and referral form; the modified Child Behaviour Checklist; maternal history of substance abuse; and the Medicine Wheel. The meconium screening and the Child Behavior Checklist are not appropriate for use in adult screening, but the other three screening tools selected – although meant for screening with children and youth – may prove useful in screening adults.

Grafman and Litvan (1999) presented a series of screening questions that can be used in the evaluation of frontal lobe (cognitive) functioning (see Appendix B). These include functional areas of impairment such as attention-concentration, predictive planning, adaptive planning, short-term planning, reasoning, thematic understanding, social skills, inhibition and motivation with their
potential prefrontal cortical area of involvement, and the neurobehavioural probe to assess specific behavioural manifestations. These are important areas of functioning that may indicate FASD impairment in adults.

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

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

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

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

How might a screening tool intended for use with children or adolescents be adapted for those who are already adults? Streissguth et al. in 1991 examined FAS in adolescents and adults and found some important differences when compared with diagnosis in children. Some of the physical characteristics described by Streissguth and colleagues could be used to adapt previous screening tools for an adult population. Also, the inclusion of more cognitive, neuropsychological and learning disabilities related to findings about FASD effects in late childhood (Streissguth, Barr, Kogan & Bookstein, 1997) could strengthen the screening for FAS and its related disorders in adults.
Screening for referral to a diagnostic clinic is an important function that would benefit from a consistent approach. Fast and Conry (2004) were clear that "screening tools for FASD need to be developed and validated" (p. 162). The purpose of such screening tools would be to identify individuals at high risk of having FAS or one of its related disorders. However, such tools should not be mistaken for or be misused to diagnose FASD. Diagnosis can be made once referral to a professional with specialized training or to a team of professionals that can administer the necessary medical and psychological assessments has taken place. There are lists of FASD diagnostic clinics and resources available for many areas (e.g., the Alberta FASD Diagnostic Clinics list put out by the Psychologists’ Association of Alberta, and the online document Creating a Foundation for FASD Diagnostic Capacity by Guilfoyle (2006) that provides a number of assessment resources in Ontario). Also, there are websites that provide information about adult diagnosis resources such as the Canada Northwest FASD Research Network’s Project Inventory, which has a description of resources and research taking place in British Columbia and Yukon.

3.2

The Diagnostic Clinic/Program

The U.S. Institute of Medicine (1996, as cited in Hoyne et al., 2005) suggested that while trained clinicians (e.g., psychologists) may diagnose the neurobehavioural aspects of FAS, dysmorphologists who are trained to assess the medical abnormalities are essential for a complete medical diagnosis. This division is reflected in much of the FASD literature where medical researchers explore the structural abnormalities and psychologists focus their research on the neurological damage incurred through in utero alcohol exposure, and the subsequent cognitive and behavioural impairments that endure (Pei & Rinaldi, 2004). The practicality related to the need to have both medical and psychological expertise in the diagnosis of FASD often presents challenges, as regular medical clinics are usually not set up for this diversity in expertise. Thus, across Canada and internationally, specialized clinics or programs have been set up to facilitate the diagnoses of fetal alcohol-exposed children, adolescents and adults resulting in FASD.
“Because there is no definitive test for FASD, researchers and clinicians diagnose FASD symptomatically and then look back to these abnormalities to better refine diagnosis”

(Pei & Rinaldi, 2004, p. 126). A multidisciplinary team for assessment is usually called upon to participate in the diagnostic process, as the symptomology for FASD is varied and some aspects change across the lifespan of the person affected (Chudley, Kilgour, Cranston & Edwards, 2007). These specialized teams may be housed in a hospital or community health clinic. Virtual and mobile teams can be created in regions where distance is an obstacle to diagnosing children, adolescents and adults with FASD (Chudley, Kilgour, Cranston & Edwards, 2007; Guilfoyle, 2006; McFarlane & Rajani, 2007). Team members usually include at minimum a physician with expertise in birth defects and different anomalies such as facial dysmorphology and other physical health issues related to FASD. A psychologist is included as part of the team, as well as a nurse clinician, social worker, occupational therapist, educators and a speech language pathologist, and may involve additional members such as family advocates if required (Boland, Chudley & Grant, 2002; Chudley et al., 2005). Diagnostic teams vary in their membership, dependent on resources available in different communities. Some resources are available to guide the establishment and team development required for such a diverse and highly trained team (Dewane, Scott & Brems, 2005). Appendix C provides a description of team member roles from the Vancouver Island Health Authority’s pilot project diagnostic clinic, which may be typical of such multidisciplinary teams.

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

Peadon, Fremantle, Bower and Elliott (2008) reported the following results. As recommended in diagnostic guidelines, assessments were completed by a multidisciplinary team in
97% of the clinics surveyed. In 94% of clinics, some members have specific training in the area of children exposed to alcohol in utero. Neurobehavioural assessments were part of the diagnostic process in 94% of the cases reported. Only 24% of the clinics had no referral criteria specified. Approximately 15% of the clinics surveyed reported that they provided diagnostic services to individuals of any age; an additional 15% were exclusively for children; and the remainder served infants, children, adolescents and a few young adults. Funding sources were queried, and it was reported that 26% of the clinics charged some form of fee-for-service. One such clinic was located in Canada and the remaining eight were in the United States. The clinics in South America, South Africa, Italy and the United Kingdom received funding from research grants and/or federal funding. These were also sources of funding used in the Canadian and American clinics. A full study of Canadian clinics and teams providing assessments to adults would add greatly to our understanding of what is already taking place in this area and could form the beginnings of a best practice model that focuses on a consistent approach to assessment and diagnosis.

### 3.3 Assessment Process and Procedures

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

Several resources described a clinic-based model where the individual is scheduled for a one-day clinic, during which all assessments are conducted by respective practitioners and a diagnosis is derived by the end of the clinic day (Dewane, Scott & Brems, 2005; McFarlane, 2008). Some psychological testing may require up to a half-day longer so the assessment is spread over a two-day period. The clinic concludes all assessments, interviews, collation of information, diagnostic determination, recommendations and report writing on clinic day (McFarlane, 2008). The diagnosis and recommendations are usually presented during
a meeting with the client and members of his or her support network. At this meeting, the team usually introduces the diagnostic code and explains the results. Team members have an opportunity to share their observations and recommendations. Questions from the individual and family or friends who are supporting the person can be addressed at this time, as well as the scheduling of any follow-up sessions and/or referrals to other community resources.

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

A. Adult Assessment and Diagnostic Project

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

B. The Asante Centre for Fetal Alcohol Syndrome

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

1. A referral to the clinic is made either as a self-referral (for which the Centre has a family nurse clinician and family support worker who will assist the person in gathering the information needed for the assessment) or physician referral. The documentation that is needed includes birth records, medical records, school records, past assessments, and confirmation of alcohol use by mother.

2. As stated in the material from the Asante Centre, the actual assessment, which takes one and a half to two days, has four components:
   a. medical assessment where a medical doctor measures eyes and other facial features, assesses fine and gross motor skills, reflexes, height, weight and hearing
   b. psychological assessment involves tests of memory, problem-solving skills, academic abilities and cognitive abilities
   c. speech and language assessment to examine communication skills and patterns
   d. interviews with the person being assessed plus other people who act in supporting roles to learn about their needs.
C. The Lakeland FASD Centre

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

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

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

Key issues for 22 adults diagnosed in this clinic between 2001 and 2004 were employment, physical health, mental health, justice issues, independent living, finances and addictions. The relevance of diagnosis is that adults who are diagnosed can be provided supports through individual planning in order to assist in negotiating these challenges in their communities.
McFarlane and Rajani (2007) provided an analysis of critical factors and challenges to the success of FASD diagnostic clinics in rural areas specifically but to all diagnostic clinics generally. Critical factors included team selection and coordination as well as the development and management of the team. A commitment to client/family-focused services and establishing cultural connections within the community were also identified as important features of a diagnostic clinic model.

3.4 Diagnostic Criteria and Decision Making

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

FASD is a series of multifaceted conditions – a wide range of characteristics, which are variable and age dependent, but which need to be considered when diagnosing FAS and its related disorders (Burd, Cotsonas-Hassler, Martsolf & Kerbeshian, 2003; Streissguth et al., 1991). Pei and Rinaldi (2004) reported that the Institute of Medicine’s report in 1996 addressed the previous lack of diagnostic clarity by identifying a range of birth defects and disabilities caused by fetal alcohol exposure. Each of these FASD categories was based on the traditional four diagnostic criteria (i.e. fetal alcohol exposure; growth deficits; neurodevelopmental and behavioural characteristics; and distinctive facial features) but with increased detail and specificity. Diagnoses under the FASD umbrella include: 1 Fetal Alcohol Syndrome (FAS), which refers to a person who has slowed growth, certain facial features and brain abnormalities; 2 Partial FAS (pFAS), which refers to individuals who have some but not all of the FAS characteristics – this was previously referred to as fetal alcohol effects (FAE); and 3 Alcohol-related Neuro-developmental Disorder (ARND), which encompasses a range of CNS dysfunctions associated with in utero exposure to alcohol. The other major category included under the FASD spectrum was Alcohol-related Birth Defects (ARBD), which was seldom mentioned in the evidence-based literature reviewed on FASD diagnosis. A breakdown by the four diagnostic types presented above was reported by a Finnish study (Autti-Ramo et al., 2006) of 77 individuals.
aged 8 to 20 years who were assessed based on physical characteristics; 95% were diagnosed with FASD with the following breakdown across the spectrum of diagnoses:

![Figure 3](image)

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

Peadon and colleagues (2008) suggested that

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

and the publication of multiple guidelines available in the past 10 years or so (p. 18). As a result, researchers and clinicians frequently use more than one set of diagnostic criteria or make their own adaptations to published guidelines according to Peadon’s survey results (i.e. almost one-third of the clinics surveyed reported this finding). A consistent approach to diagnosis, including best practice evidence for assessment tools and techniques with adults, would greatly advance this field, and make for more readily accessible comparisons among research and practice findings.

Leading practice on diagnosis of FASD has emerged in North America from the standards set by the U.S. Institute of Medicine (Stratton, Howe & Battaglia, 1996) and the 4-Digit Diagnostic Code (Astley & Clarren, 1996). Diagnosis relies heavily on classification systems, which provide a portrait of the characteristics that constitute a particular condition or disease. Astley and Clarren, using the Washington State FAS Diagnostic and Prevention Network statistics, developed a new, comprehensive, reproducible method for diagnosing the full spectrum of outcomes of patients with fetal alcohol exposure. This new diagnostic method, called the 4-Digit Diagnostic Code, provided more accurate and reproducible diagnoses using quantitative, objective measurement scales and specific case definitions. The four digits in the code reflect the magnitude of expression of the four key diagnostic features of FAS: 1. growth deficiency, 2. the FAS facial features, 3. central nervous system (CNS) damage/dysfunction, and 4. fetal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale (i.e. 1 refers to the complete absence of the FAS feature and 4 to a strong “classic” presence). An individual’s 4-Digit Diagnostic
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Code is derived after a thorough evaluation by an interdisciplinary team of professionals. This diagnostic tool has been used in numerous research and clinical cases, and has been adopted as the preferred assessment tool in the Canadian guidelines for diagnosis of FASD. Astley (2003) indicated that “over 50 multidisciplinary clinical teams across the United States and Canada are now using the 4-Digit Diagnostic Code in a wide array of clinical/social service settings” (p. 3). Chudley, Kilgour, Cranston and Edwards (2007) noted that “modifications of the 4-Digit Code are being used in many clinics throughout North America for use in the diagnosis of children and adults” (p. 264).

However, when assessing adults with potential FASD, adjustments are needed to our current understanding and assessments. (Chudley, Kilgour, Cranston & Edwards, 2007). Burd, Cotsonas-Hassler, Martsolf and Kerbeshian (2003) developed an instrument for assessing the severity of FAS and its related disorders (pFAS and ARND) in children, adolescents and adults (age range 1 month to 56 years). This preliminary instrument (see Appendix E) measures areas such as growth, facial features, comorbid neuropsychiatric conditions, sleep, services used and Vineland scores (i.e. Vineland Adaptive Behavior Scales), and is based on empirical evidence that comorbid mental disorders are strongly associated with diagnoses of FAS or pFAS. These authors urge the research and practice communities to lessen their reliance on dysmorphia (facial features and growth impairment such as short palpebral fissure or absent philtrum) as the essential diagnostic feature of the spectrum of FAS and pFAS in favour of “the primary problem from prenatal alcohol exposure is brain damage or dysfunction manifesting as common disorders of development and as mental illness” (p. 704).

A. Evaluating Dysmorphology

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

The traditional physical examination for dysmorphology would include growth measurements for height, weight and head circumference (Streissguth et al., 1991). FAS shifts the normal distribution of height and head circumference about two standard deviations down from the population mean for adolescents and adults. However, Streissguth et al. (1991) found that
28% of their sample of adolescents and adults had normal head sizes, and 16% were within the average height range. FAS has been shown to have less consistent effects on weight, even though being underweight is very typical in young children with this disorder. Among the adolescents and adults in this 1991 study, 25% of those with FAS diagnosis and 50% of those with FAE (now known as pFAS) were not underweight. There were no gender differences on growth parameters noted, and no significant delay in the onset of puberty.

The other classical examination for characteristic facial features (i.e. short palpebral fissures, midface hypoplasia, smooth and/or long philtrum and thin upper lip) provides specificity for FAS but not other diagnoses within the spectrum (Streissguth et al., 1991). These facial features have been found to be among the most variable of the characteristics across FAS development (Burd, Cotsonas-Hassler, Martsolf & Kerbeshian, 2003). Streissguth et al. (1991) noted that facial characteristics became less distinctive over time, although these authors suggested that in many adolescent and adult cases “eye anomalies, short palpebral fissures, and abnormalities of the philtrum and lips remain useful diagnostic feature” (p. 1964). However, there was continued growth in four facial areas mentioned in this study: 1. nose in two dimensions – height of the nasal bridge and nasal length from root to tip; 2. growth of the midfacial region correcting the earlier midfacial hypoplasia; 3. improved soft-tissue modelling of the philtrum and upper lip; and 4. continued growth of the chin.

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

B. Evaluating Brain and Neurological Abnormalities

The neuroanatomical effects of in utero alcohol exposure are well documented in the research literature. A series of research studies has investigated the CNS anomalies associated with FAS and its related disorders to better understand the brain functioning. Anatomical abnormalities in areas such as the corpus collosum, cortices and basal ganglia have been linked to developmental and behavioural deficits such as intelligence, language development, visual-spatial functioning and attention/memory problems (Bookstein,
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Developments in magnetic resonance imaging (MRI) and functional magnetic resonance imaging (fMRI) technologies have made the mapping of these abnormalities in children, adolescents and adults more accurate and readily accessible (Swayze et al., 1997). For example, Malisza et al. (2005) evaluated the spatial working memory function of both children and adults with FASD using the fMRI technology. These researchers found that adults with FASD showed increased functional activity in the inferior and middle frontal cortex compared with the activity in age- and sex-matched controls. Sowell et al. (2002) found that brain growth continues to be adversely affected well into adulthood. The regions most affected by fetal alcohol exposure were frontal and inferior parietal, and may account for some of the behavioural deficits characterized by those affected by FASD. The maintenance of structural brain changes into adulthood led Bookheimer and Sowell (2005) to investigate the effectiveness of a functional (i.e. in assessing brain activation during working memory tasks) and structural MRI in adults with FASD. A challenge faced with fMRI results is that not enough data are available with control subjects to make a clear assessment of what level or magnitude of activation of specific brain functions is indicative of FASD impairment.

Using a related technology, the Fagerlund et al. (2006) study examined the brains of 10 adolescents and young adults diagnosed with FASD using magnetic resonance spectroscopy (MRS), and suggested that exposure to alcohol in utero appears to permanently alter brain metabolism (neurochemical alterations) in multiple areas of the brain (e.g. parietal and frontal cortices, corpus callosum). These findings provide support for the executive functioning deficits found by Kodituwakku, Kalberg and May (2001) and Mattson, Schoenfeld and Riley (2001), who found that individuals with FASD experienced difficulties with problem solving, and planning and flexibility in terms of thought processes.
Riley, McGee and Sowell (2004) summarized a decade of using brain imaging techniques to assess brain functioning with children and adults diagnosed with FASD. They concluded that microcephaly and structural abnormalities affecting the cerebellum, corpus collosum and basal ganglia were common in alcohol-exposed individuals. Most recently, Sowell et al. (2008) have used MRIs to investigate the patterns of brain dysmorphology in children and young adults. In this research, they are finding new associations between cortical thickness in certain areas of the brain in individuals with FASD when compared with controls. In the future, diagnostic testing may use brain imaging techniques to further our understanding of the mechanisms involved in the behavioural deficits long acknowledged in people with FASD.

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

C. Evaluating Neurodevelopmental and Neurobehavioural Deficits

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

(Mattson & Riley, 1997, p. 4). Even so, “many symptoms are non-specific and no neurodevelopmental profile has been developed” reported Malisza et al. (2005, p. 1150). These researchers found that adults with FASD showed increased functional activity in the inferior and middle frontal cortex compared with the activity in age- and sex-matched controls.

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

- **Microcephaly or history of developmental delay** (Streissguth et al., 1991)
- **Attention deficits** (Kerns, Don, Mateer & Streissguth, 1997; Streissguth et al., 1991)
- **Cognitive, learning and/or intellectual deficits** (Kerns, Don, Mateer & Streissguth, 1997; Streissguth et al., 1991)
- **Seizures** (Streissguth et al., 1991)
- **Auditory and visual attention** (Chan, 1999; Connor, Streissguth, Sampson, Bookstein & Barr, 1999)
- **Verbal memory function** (Kerns, Don, Mateer & Streissguth, 1997)
- **Motor control** (Connor, Sampson, Streissguth, Bookstein & Barr, 2006)

Individuals with FASD often have many neurobehavioral problems which interrelate to cause profound problems with accurately processing information and in their relationship with the world around them. Impacting adult functioning are problems with impulse control and discerning cause–effect relationships; problems with the ability to generalize information; problems...
with understanding concepts and abstract thinking; problems with short-term memory; and problems with processing information, particularly auditory information.

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

Very little consistency in assessment tools and techniques was found in the clinical research literature for assessing academic and adaptive functioning. For example, the Addiction Severity Index (5th ed.), which assesses problem severity in seven domains, including medical, employment, legal, family/social, alcohol and other substance abuse, and psychiatric/emotional was used by Grant, Huggins, Connor and Streissguth (2005), but not in any other research examined. In the same study, Grant and colleagues found that of the 11 women administered the Brief Symptom Inventory (53-item psychiatric symptom checklist), 55% were found to have symptom levels indicative of a psychiatric diagnosis. This finding was consistent with that of Famy, Streissguth and Unis (1998) but they used a different instrument to measure depression. In the follow-up study by Streissguth et al. (1991), the Vineland Adaptive Behavior Scale was used to assess adaptive functioning in people previously diagnosed with FAS. Assessment using this measure of adaptive functioning in the areas of daily living, socialization and communication skills indicated an average level of adaptive functioning at around seven years for the adolescents and adults involved in the study. This testing revealed problematic deficits in “failure to consider consequences of actions, lack of appropriate initiative, unresponsiveness to subtle social cues, and lack of reciprocal friendships” (p. 1965). All participants in this study were assessed to have either a “significant” level of this maladaptive behaviour (62%) or an “intermediate” level of dysfunction (38%). Poor concentration and attention dependency, stubbornness or sullenness, social withdrawal, teasing or bullying, crying or laughing too easily, impulsivity, and periods of high anxiety were
among the maladaptive behaviours noted. It is these types of adaptive deficits that are the focus of the next section.

D. Evaluating Secondary Sequelae

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

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

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

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

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

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

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

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

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

- **substance abuse** (Chudley, Kilgour, Cranston & Edwards, 2007; Clarke, Tough, Hicks & Clarren, 2005; Famy, Streissguth & Unis, 1998; Lemoine, 2003)
Exclusive to adults were three additional secondary conditions: dependent living, problems with employment and problems parenting their children. While the above present more as social problems, the following are more reflective of a secondary disability, particularly those diagnoses related to mental health. The Famy, Streissguth and Unis (1998) study of 25 adults with diagnosed FAS or FAE found that 92% met criteria for past or present alcohol or drug dependency; 48% for personality disorders, especially avoidant, dependent or antisocial personality disorders; 44% for depression; 40% for psychotic disorders; and 20% with bipolar and anxiety disorders.

Mental health problems associated with FASD have received a great deal of attention in the literature (e.g. Barr et al., 2006; Bhatara, Loudenberg & Ellis, 2006; Boland, Chudley & Grant, 2002; Streissguth, Barr, Kogan & Bookstein, 1997; Wright and Associates, 2004). Barr et al. (2006), in a 25-year longitudinal study of over 400 alcohol-exposed individuals (compared with those whose mother smoked cigarettes while pregnant), found that alcohol-exposed individuals were more than twice as likely to receive a diagnosis of somatoform disorder, substance dependence or abuse disorder, paranoid, passive-aggressive and antisocial personality disorders or traits, and other personality disorders than those in the comparison group. However, there is no causal link between the primary and secondary conditions. Dubovsky (2008) cautioned of the possibility of misdiagnosis as alcohol-related neurodevelopmental disorders can look like many other mental health diagnoses or developmental disabilities. Making a differential diagnosis for FASD rather than any of the myriad other possibilities is primarily reliant on a history of maternal alcohol use during pregnancy.

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

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

In contrast to the disruptive educational experience reported by Streissguth et al., 1997 are the findings of Duquette, Stodel, Fullarton and Hagglund (2006). In a qualitative study
of eight adolescents/young adults (aged 15 to 20), Duquette and colleagues collected information about the subjects’ diagnosis and individual characteristics, as well as their school experiences, academic progress, and social connectedness through questionnaires and in-depth interviews. They found that parental expectations of completing high school, support and advocacy directly influenced the individual’s persistence in remaining in school.

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

3.5

Challenges in Diagnosing Adults

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

Chudley, Kilgour, Cranston and Edwards (2007) remind us that “only FAS can be diagnosed without information on prenatal alcohol exposure” (p. 263). In individuals with cognitive and behavioural difficulties (but lacking the distinctive facial features and in the absence of fetal alcohol exposure confirmation), an FASD-related diagnosis cannot be easily made. This
is particularly troublesome, when considering adult assessment, as facial dysmorphology may disappear as the person ages (Streissguth, Barr, Kogan & Bookstein, 1997; Streissguth et al., 1991) and records or recollections of maternal alcohol use during pregnancy may not be available (Chudley, Kilgour, Cranston & Edwards, 2007; Fast & Conry, 2004). Informative birth records, which could provide information about the amount of alcohol intake during pregnancy, may not be available or are non-existent. Reliable models of information gathering could assist in diagnosis.

3.6 Follow-Up to FASD Diagnosis

Through our review of the literature in relation to adults, it is evident that the issue of adult diagnosis is addressed in a limited fashion, that a consistent approach is difficult to identify and the financial infrastructure to support adult diagnosis does not presently exist in the public domain. Private clinics do exist that engage in screening and adult assessment, such as the Asante Centre in British Columbia, Lakeland Centre for FASD, The OBD Triage Institute and Medigene in Alberta, yet some people seeking diagnosis may not have the financial resources to access services on a fee-for-service basis.

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

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

4.1 Strengths of the Literature

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

4.2 Limitations and Gaps in the Literature

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

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

Astley (2003) presented an argument for the need for “an accurate and reproducible method of diagnosis” in children (p. 2). In that argument, she raised a number of points that are as valid
today in terms of the lack of clear and replicable adult diagnostic methods. Astley presented her arguments from three perspectives, and they have been adapted here with adults with FASD in mind. First, from a clinical perspective, the individual who may be misdiagnosed would receive inappropriate intervention and support, and be at increased risk for secondary consequences of FASD. From a public health perspective, true prevalence rates for FASD remain hidden when people remain undiagnosed or are misdiagnosed, which can lead to the thwarting of funds needed to deal adequately with the health care, social and educational needs of adults with FASD. Finally, from a clinical research perspective, inaccurate diagnosis reduces the ability of researchers and users of research to make meaningful comparisons between different groups, and

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

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

While there are some suggestions for accurate screening and diagnostic methods based on those that have been successful with children and adolescents, to date there is no methodology in either screening or diagnostic method that is used across multiple practice or research situations.

There is limited information on the prevalence rates of FASD in adults. This is, in part, because there are no reliable biological markers that readily define those affected, especially with diagnoses other than FAS. Estimates of FAS occurrence vary from 1 to 4.8 per 1,000 live births and approximately 9 per 1,000 live births if all the diagnostic categories for FASD are included (Sampson et al., 1997). This is assumed to underrepresent the actual incidence (Sokol, Delaney-Black & Nordstrom, 2008). The variability in rates is, in part, due to the lack of uniformity in what is accepted as the diagnostic criteria for those who lack the dysmorphic features – the high proportion of adults and children with ARND, for example.
4.3

Implications for Practice

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

It is a challenge to diagnose adults without an existing infrastructure in policy and practice that supports this community need. A focus on diagnosing children with FASD has raised awareness that similar needs exist for adults. One of the key issues for adults, particularly those from homes where alcoholism was a serious issue, is that retrospective information regarding their own in utero history may not be readily available. Diagnostic guidelines clearly state that "prenatal alcohol exposure requires confirmation of alcohol consumption by the mother" (Chudley et al., 2007, p. S11). Discovering this information requires protocols that are sensitive to adults who have traumatic histories.

Another area that will affect practice is the development of support services specifically for adults living with FASD. These support services will be of increasing importance as more adults are diagnosed with FASD and those diagnosed as children and adolescents age. Stonehocker (2007) prepared an evaluation of an adult support coordinator program associated with the Lakeland Centre for FASD in Cold Lake, Alberta. She assessed client, caregiver, service provider, and systems outcomes. Gaps in services recognized through this evaluation were in the areas of supervised emergency housing, transportation, medical care, supported living, and transition planning to adult services. These issues can be addressed only with significant interaction and awareness with municipal authorities.
Educational programs for various professionals who might be involved in screening and referring adults for complete diagnostic assessment (e.g. primary care physicians and other health care professionals, educators, mental health professionals, social service workers and professionals in the justice system) must be developed. Sharpe et al. (2004) suggested the need to develop FAS regional training centres as well as educational curricula for medical and allied health professionals that incorporate evidence-based diagnostic guidelines for FASD. Increasing training could directly impact an increased capacity for screening, diagnosing and supporting adults living with FASD. This need is supported by a Canadian survey of pediatricians, psychiatrists, obstetricians, midwives and family physicians conducted by Clarke, Tough, Hicks and Clarren (2005). They recognized that “there is a great need to help providers recognize the primary and secondary disabilities of FASD especially in affected individuals who do not have mental retardation or dysmorphic features as part of their diagnosis” (p. 12).

Several training manuals and practical guidelines already exist (e.g. FAS at Street Level: Fetal Alcohol Spectrum Disorder and Homelessness (Stade, Clark & D’Agostino, 2004), Psychosocial Needs Associated with Fetal Alcohol Syndrome: Practical Guidelines for Parents and Caretakers (Ladue, 1993), Neurobehaviour in Adolescents and Adults (FAS Community Resource Center, n.d.), and Fetal Alcohol Spectrum Disorder: A Learning Module for Health and Social Service Workers (Capital Health Edmonton and Area, 2005). These could be used and other resources developed to increase awareness of FASD with a focus on the adult population. A secondary issue related to consistency of knowledge/education about FASD is that people have been informed differently through various educational opportunities related to FASD and may apply this knowledge differentially, thus causing inconsistencies in response to FASD.

4.4 Implications for Policy

Through our review of the literature in relation to adult diagnosis and assessment, it is evident that the issue of adult diagnosis is addressed in a limited fashion, that a consistent approach is difficult to identify, and that the financial infrastructure to support adult diagnostic clinics and teams do not presently exist in the public domain. Private clinics do exist that engage in adult assessment, such as the Asante Centre in British Columbia, The OBD Triage Institute and Medigene in Alberta, but the cost for the assessment is often in the range of $1,000 to $5,000 or more. Some clinics are able to fundraise or use research dollars to support the assessment process and thus do not have to pass the cost along to others. However, if accessible diagnosis is to be available, then more sustainable funding needs to be in place. If the provincial government strategic plans for “timely
diagnosis, assessment and planning for children, youth and adults affected by FASD” (Fryer, 2005, p. 6) is to be fulfilled, then policy must direct that diagnostic services be covered by universal health care rather than left as a cost burden on the individual or his or her family.

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

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

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

4.5

Implications for Research

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

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

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

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

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

### 4.6 Conclusions and Recommendations

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

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\(^4\) www.canfasd.ca/
a world that does not know how to respond to individuals who “talk better than they do,” as Nathan Ory said in Yellowknife, NWT in 2005.

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

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

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

Key strategies for intervention with adults diagnosed with FASD are emerging within the Canadian experience. First, there is a need to include trauma-informed practices with adults living with FASD, which implies the need for
screening and diagnostic protocols that are sensitive to the needs of individuals. Second, the need exists for a greater understanding and careful assessment of addictions and substance abuse issues for undiagnosed adults. Third, ongoing knowledge development of adult-specific responses, particularly related to neurocognitive and neurobehavioural disorders, is needed. Understanding how adults with FASD process auditory information, for example, is a key point to develop better practice and offer a consistent framework of response across each province and territory. Accurate and effective diagnosis and intervention fosters healthier individuals, families and communities. Another key strategy would be to provide opportunities and the ability for adults with FASD to negotiate required supports in different systems. It is important that those working in the field with children, adolescents and adults with FASD become informed about the complexity of this disabling condition and develop models and frameworks of a complex case management response through the better use of case studies as learning opportunities. Knowledge exchange among different professions working in this area is another strategy that would provide a deeper understanding of the complexity of this disabling condition. For example, social workers need to know more about how to meaningfully interpret psychological evaluations while other professionals would benefit from a clearer understanding of the psychosocial implications of living with an FASD. This exchange would be helpful in advancing the knowledge base related to FASD if each of the disciplines involved leads to a better understanding of each other’s roles in the screening, assessment and diagnosis of FASD and a better informed professional response system. Additionally, it is important to strengthen the linkages between frontline workers and those engaged in diagnosis. Although adult diagnosis does occur in a fashion, there is a generalized perception that this is a service not available in Canada. Finally, strong advocates have emerged on the Canadian landscape to recommend adult diagnosis – Lutke, Clarren, Lawryk, McFarlane, Riley, and Ory for example. Let us build on their expertise and develop the next generation of researchers and practitioners who are knowledgeable about and sensitive to the experiences of adults living with FASD.
Bibliography


Mattson, Sarah N., & Riley, Edward P. (1997). Neurobehavioral and neuroanatomical effects of heavy prenatal exposure to alcohol. In Streissguth Ann, & Kanter, Jonathon (Eds.), *The Challenge of*


**Appendix A:**
**FAS screening form**

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

Name ____________________ DOB ____/____/____  Age _____ Sex (circle one) F M

Date of Exam ____/____/____

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

Height ________________ inches  <5% Y ____ N ____ 10

Weight ________________ pounds  <5% Y ____ N ____ 10

Head Cir. ________________ cm  <5% Y ____ N ____ 10

<table>
<thead>
<tr>
<th>Head and face</th>
<th>Y____ N____</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ears stick out (protruding auricles)</td>
<td>Y____ N____ 4</td>
</tr>
<tr>
<td>Skin folds near inner eye (epicanthal folds)</td>
<td>Y____ N____ 5</td>
</tr>
<tr>
<td>Drooping of eyelids (ptosis)</td>
<td>Y____ N____ 4</td>
</tr>
<tr>
<td>Crossed eyes – one or both eyes (strabismus)</td>
<td>Y____ N____ 3</td>
</tr>
<tr>
<td>Flat midface/cheeks (hypoplastic macila)</td>
<td>Y____ N____ 7</td>
</tr>
<tr>
<td>Flat/low nose between eyes (low nasal bridge)</td>
<td>Y____ N____ 2</td>
</tr>
<tr>
<td>Upturned nose</td>
<td>Y____ N____ 5</td>
</tr>
<tr>
<td>Groove between lip and nose absent or shallow (flat philtrum)</td>
<td>Y____ N____ 5</td>
</tr>
<tr>
<td>Thin upper lip</td>
<td>Y____ N____ 4</td>
</tr>
<tr>
<td>Cleft lip or cleft of roof of mouth (present or repaired)</td>
<td>Y____ N____ 4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Neck and back</th>
<th>Y____ N____</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short, broad neck</td>
<td>Y____ N____ 4</td>
</tr>
<tr>
<td>Curvature of the spine (scoliosis)</td>
<td>Y____ N____ 1</td>
</tr>
<tr>
<td>Spina bifida (history of neural tube defect)</td>
<td>Y____ N____</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
<tr>
<td>------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Arms and hands</td>
<td>Fingers, elbows (limited joint mobility)</td>
</tr>
<tr>
<td></td>
<td>Permanently curved, small fingers, especially pinkies (clinomicrodactuly)</td>
</tr>
<tr>
<td></td>
<td>Deep or accentuated palmar crease</td>
</tr>
<tr>
<td></td>
<td>Small nails/nail beds (hypoplastic nails)</td>
</tr>
<tr>
<td></td>
<td>Tremulous, poor finger agility (fine motor dysfunction)</td>
</tr>
<tr>
<td>Chest</td>
<td>Sunken chest (pectus excavatum)</td>
</tr>
<tr>
<td></td>
<td>Chest sticks out (pectus carinatum)</td>
</tr>
<tr>
<td></td>
<td>History of heart murmur or any heart defect</td>
</tr>
<tr>
<td>Skin</td>
<td>Raised red birthmarks (capillary hemangiomas)</td>
</tr>
<tr>
<td></td>
<td>Greater than normal body hair, hair also on forehead and back (hirsutism)</td>
</tr>
<tr>
<td>Development</td>
<td>Mild to moderate mental retardation (&lt; 70)</td>
</tr>
<tr>
<td></td>
<td>Speech and language delays</td>
</tr>
<tr>
<td></td>
<td>Hearing problems</td>
</tr>
<tr>
<td></td>
<td>Vision problems</td>
</tr>
<tr>
<td></td>
<td>Attention concentration problems</td>
</tr>
<tr>
<td></td>
<td>Hyperactivity</td>
</tr>
</tbody>
</table>

Comments: Score total _______

Refer if 20 or above
## Appendix B: Evaluation and management of frontal lobe functions

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

### Evaluation and management of frontal lobe functions

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

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

* If screening identified potential areas of impairment, specialized testing by a neuropsychologist, neuropsychiatrist, or behavioral neurologist is usually required.
Appendix C:
Multidisciplinary Team Roles

Source: Fryer (2008, p. 9)

Occupational Therapy

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

Social Worker

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

Physician

- Provides diagnosis in the medical context
- Recognizes additional risk factors, conducts a physical examination
- Provides differential diagnosis
Speech Language Pathologist

Provides screening level assessment for language issues

Neuropsychology

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

Family Support Worker

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

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

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

Provides education to those in the child's community to reframe their approach to the child.
## Appendix D:
### Pre-Assessment Checklist

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

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

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

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

**Obtaining records:**
- [ ] Secure signed release of information forms
- [ ] Use telephone, fax, or mail for making request
- [ ] Learn the most effective way to request records from different facilities
- [ ] Remember that gathering information from other agencies will improve the diagnostic process and may reduce assessment time
Appendix E:
FASD Diagnostic Checklist

Severity score for FAS and related disorders

<table>
<thead>
<tr>
<th>1. Growth</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Height</td>
<td>= 10 – height percentile</td>
</tr>
<tr>
<td>Weight</td>
<td>= 10 – weight percentile</td>
</tr>
<tr>
<td>Head circumference</td>
<td>= 10 – head circumference percentile</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Facial Features</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of features</td>
<td>1 point for each</td>
</tr>
<tr>
<td>Number of anomalies</td>
<td>1 point for each</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Neuropsychological</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Comorbid neuropsychiatric conditions</td>
<td>2 points for each</td>
</tr>
<tr>
<td>IQ</td>
<td></td>
</tr>
<tr>
<td>&lt;85</td>
<td>4 points</td>
</tr>
<tr>
<td>&lt;70</td>
<td>8 points</td>
</tr>
<tr>
<td>&lt;50</td>
<td>10 points</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Neurobehaviour</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep (consecutive hours, select one)</td>
<td>1 point</td>
</tr>
<tr>
<td>&lt;6</td>
<td>1 point</td>
</tr>
<tr>
<td>&lt;4</td>
<td>5 points</td>
</tr>
<tr>
<td>&lt;2</td>
<td>10 points</td>
</tr>
</tbody>
</table>
5. Vineland scores

<table>
<thead>
<tr>
<th>Score Area</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 – communication score</td>
<td>+ 10</td>
</tr>
<tr>
<td>10 – daily living score</td>
<td>+ 10</td>
</tr>
<tr>
<td>10 – socialization score</td>
<td>+ 10</td>
</tr>
<tr>
<td>10 – motor skills score</td>
<td>+ 10</td>
</tr>
</tbody>
</table>

6. Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foster care placement</td>
<td>3 points each</td>
</tr>
<tr>
<td>Inpatient hospital care</td>
<td>1 point each</td>
</tr>
<tr>
<td>Criminal justice</td>
<td>1 point each month probation/ incarceration</td>
</tr>
<tr>
<td>Special education</td>
<td>1 point each hour of service per day</td>
</tr>
<tr>
<td>Residential care</td>
<td>1 point each month in the last year</td>
</tr>
</tbody>
</table>

FAS Phenotype Score: 1 + 2 + 3
FAE Phenotype Score: 3 + 4 + 5 + 6
Total Score
Report on Supportive Housing Opportunities for Adults with FASD

By: Coleen Burns

Lakeland Centre for FASD

An Alberta FASD Service Network

Edited by: Lakeland Centre for FASD

Background

Adults living with Fetal Alcohol Spectrum Disorder (FASD) can face multiple barriers and challenges in their attempts to secure one of the most basic of needs, appropriate housing. For many adults with FASD, access to supports and services that assist with daily living is futile without the foundation of adequate housing. Adults living with FASD display as many variances in their abilities and deficits as the spectrum disorder defines. The housing needs of this population also vary according to the degree of central nervous system damage and the presence or absence of secondary disabilities that are predominant in so many adults with FASD. A range of housing options is needed to establish a framework of stability and security for these adults, which can be as variable as their strengths and challenges. Despite individual differences in their disabilities, there is common ground among all in their need to have supported, safe, stable, consistent and affordable housing.

There are few supportive housing options for caregivers of youth with FASD when planning for transitions from adolescence to adulthood. The absence of suitable housing resources during this critical period shifts the weight of providing supported housing to the biological, adoptive or extended family, if the youth or adult is fortunate enough to have these resources. Sadly for many, the roof over their head is often a correctional facility, short-lived stay with family or friends or, drifting into a homeless cycle and living on the streets.

Optimally, when adults with FASD have their housing needs met the some of the burdens on their caregivers is minimized and the affected individuals can begin to focus on options for other areas of their life. Various emerging models of supportive housing for adults with FASD are being explored and developed in communities across Canada (Burns, C. 2008; Brownstone, L. 2005). Some of these models are transitional housing, others allow residents to build home equity through ownership, and many are specific for individuals such as single parents, males in the justice system or those struggling with addictions. Low-barrier housing offers some housing solutions for those who cannot meet certain eligibility criterion prior to accessing housing, such as
being drug and alcohol-free, or participating in rehabilitation programs. Unfortunately, a common link with many housing projects is lack of sustainable, start up funding, staffing challenges, inaccurate perception or a lack of understanding of FASD by the neighbourhoods or communities where the residents live, and the ineligibility of FASD clients meeting supportive living program guidelines (i.e. based on functional and/or I.Q. levels). The effectiveness of housing models is most evident when the service delivery meets the needs of the individuals and communities being served. Ultimately, an understanding of the disability, the presence of strong community and stakeholder partnerships, removing many of the barriers that exist before one is eligible for housing and having sustainable funding are paramount for successful housing outcomes for adults with FASD.

This report will examine options for supportive housing for adults with FASD, with specific reference to the Lakeland-Cold Lake service area. Information includes: 1) an overview of issues facing this population, including secondary disabilities; 2) a brief description of the geographic service region as it pertains to this topic; 3) challenges in the absence of appropriate housing; 4) description of current social housing resources in the area and the discussion of the need for supportive housing for adults with FASD; 5) opportunities and challenges for development of supportive living resources in this region.
Adults Living with FASD: Why is it so difficult?

Over recent years there has been documentation of the struggles that adults with FASD face. Many currently diagnosed children and youth entering the transitional stage to adulthood have been receiving housing, financial, educational or program support and services prior to adulthood. For those in the foster care system, housing was a provision that was not usually placed on the youth to secure. When many of the youth in this system turn the age of majority (in Alberta, 18 years old), many of the resources provided to them come to a sudden halt. There is much debate over the level of planning or preparation given to youth with special needs or disabilities who are exiting child welfare systems and having to navigate the process of finding housing that will support them. For young adults with FASD, the task can be daunting, especially when the resources in their community are absent. Adults who may be affected by FASD or those who have never received a medical diagnosis, are often entrenched in systems that do not understand their disability or do not have the services or supports that can assist with their needs, such as housing. Even though these individuals do not always have a formal FASD diagnosis, or they are considered to be “higher functioning”, most are just as vulnerable in developing secondary disabilities as those with a medical diagnosis of FAS.

“Primary disabilities are those that the child is born with. They reflect the CNS (Central Nervous System) dysfunction inherent in the diagnosis. Secondary disabilities are those that an individual is not born with and that could presumably be ameliorated through better understanding and appropriate interventions” (Streissguth, A. 1997).

The following statistics shed light on the magnitude of issues and prevalence of those living with FASD:

*The rate of FASD in North America is estimated to be 1/100 or 1% of the population (includes full FAS, Partial FAS and Alcohol Related Neurodevelopment Disorder (ARND). This estimate is considered conservative. (May, Gossage. Estimating the Prevalence of Fetal Alcohol Syndrome, Alcohol Research and Health. The Journal of the
The average IQ in FASD is between 75 and 85, with the full range in FASD between 20 and 140+. Almost all individuals with FASD have an AQ<70 (adaptive quotient, measure one's ability to function day to day without supports in the areas of communication, socialization, daily living, time management, employment, etc.). (Russel, IQ—It Just Doesn’t Matter: The Role of Adaptive Functioning in Individuals with FAS/FAE/ARN. FASD Conference: Doing What Works, Vancouver 2003)

For adults with FASD, 80% are unable to live independently, regardless of IQ. (Streissguth, Bar et al. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE); Centers for Disease Control and Prevention Grant no. RO4/CCR008515)

The apartment/Rental Accommodation profile for Cold Lake as of September 2005—0.6%

In a report by the City of Cold Lake Economic Development Advisor Committee Affordable Housing Report (2006), affordable housing gaps were listed as priority and identified the need for supportive housing for those with disabilities.

At age 18, a new set of obstacles and challenges meet these young men and women, yet the supports identified as being necessary and lifelong in nature often fall short. Copeland and Rutman (1996) researched issues facing adolescents and young adults with FASD. Participants, their caregivers and involved professionals were interviewed and findings looked at “…specific impact that FAS/E has on learning, independent living, pregnancy and parenting and dealing with the human services systems” (1996:65). Ann Streissguth, a leader in FASD research at the University of Washington, has done much to heighten the awareness of prenatal exposure and its impacts for later development in the lives of those affected.

A four-year study on secondary disabilities looked at six different identified secondary disabilities in the research population, ages 6-51 years old (Streissguth, Barr, et al., 1996). These included: mental health problems, disrupted school experiences, trouble with the law, confinement (i.e.: jail, mental health programming, inpatient drug or alcohol treatment programs), inappropriate sexual behaviour, alcohol and other drug problems.
This study also recognized other common occurring secondary disabilities in adults with FASD that put them at risk, including: being under employed; victims of violence; parenting and relationship issues; and inappropriate or absence of housing.

Nathan Ory describes cognitive factors in adults with FASD.  (Why adults with FASD don’t get better...What you see is not what you get.  March 2004, *Adults with Fetal Alcohol Spectrum Disorders: Swimming Upstream, A Reality Check. Vancouver, BC*)

These cognitive factors include:

*Wide range between relative strengths and weaknesses (Looks and sounds “smart”, acts disabled).

*Wide variability of function within day/week.

*Fluctuating attention and ability to focus.

The challenges in locating and maintaining basic housing for adults with FASD are at times insurmountable and unrealistic. For an adult with no disability, the task of finding rental or other housing in a tight rental market can be daunting, even when they are utilizing strong organizing, communicating, budgeting, decision making and problem solving skills. Adults with FASD often face frustration and confusion with the task of finding appropriate housing, and at times this can be compounded by landlords unwilling to rent without references, background checks and security deposits. Often these adults are not seen as having a disability and for many that are undiagnosed with the disorder they may not be eligible for supported housing resources. With lack of planned transitions or available adult resources or supportive housing, they may have to rely on family to provide the residence piece of the puzzle. This can result in families being financially burdened, with absence of respite resources to access, and being faced with a fear of not knowing who will provide safe housing for their adult child when family is no longer able to.
When adults are struggling with secondary disabilities, the business of finding supportive, safe, affordable housing is difficult unless communities have a plan and can provide appropriate resources to meet the spectrum of needs.

Most supportive housing for adults with disabilities is defined as being a shared home or group homes models. In some supportive housing resources, residents may have met eligibility criterion to receive a designated number of hours per week of support from individual workers, such as Person’s with Developmental Disabilities (PDD) contracted services. In many of these instances, adults with FASD are living with family or are living in independent housing, with few other constant onsite resources. Group home models are not always the most appropriate choice of those with FASD, even if they are eligible for this type of housing. Housing and outreach programs that offer a variation of on and off site support, and an environment of social cohesion, efficacy and a sense of belonging and pride in their community are optimal goals for programs and agencies looking at housing solutions for this group of adults. Throughout Alberta, including Northeast Alberta, groups are looking at developing strategies to provide alternative models of delivery for those adults challenged in finding appropriate supportive housing.
Service region—Potential for services and programs

The Lakeland area, including Cold Lake, Bonnyville, Lac La Biche, Smokey Lake, St. Paul, the seven surrounding First Nation Communities and four Metis Settlements is expanding and has seen economic and population growths over the recent years. In 2006, the City of Cold Lake had a population of 11,991, with 8.7% identified as aboriginal. In 2007, the population had grown to 12,860, with 38.5% of the population aged 18 – 40 years. The economy base is strongly linked to the military base at Cold Lake and oil and gas exploration. The majority of people living in Cold Lake have single residence dwellings, with low rental vacancy rates. One bedroom apartments exceed $600.00/month rent; the rental allowance for a single person on AISH is $255.00/month. Bonnyville, located between Cold Lake and St. Paul, has a population of 5896 and has continued to see a growth in industry and population. St. Paul, population of 5100, has a solid economy base of agriculture and service industry and some oil and gas related employment.

The communities within this region have established human services agencies and not-for-profit groups that provide a spectrum of services for seniors, disabled, youth with special needs, and the unemployed. There is potential for these communities to be leaders in models of supportive housing for adults with FASD, as Lakeland Centre for FASD (LCFASD) has strong connections with stakeholders in the area and a proven record of providing resources and programs for supporting youth and adults with FASD.

The service region of Lakeland Centre for FASD’s diagnostic clinics and other programming include Cold Lake, Bonnyville, Smokey Lake, St. Paul, Lac La Biche, and seven surrounding First Nation and Metis communities. Lakeland Centre for FASD provides mobile FASD diagnostic clinics for youth and adults throughout the Lakeland service area, with a unique service delivery model to rural communities. Since the year 2000, LCFASD diagnostic clinics have seen 254 children and 45 adults throughout the region. In addition to diagnostic clinics, LCFASD continues to provide FASD awareness, education, prevention campaigns, and continuum of care service for the diagnosed and their family. The Society also delivers evidence based training to
service providers, caregivers and professionals across the area. However a solid knowledge base in the community and awareness of issues for those with FASD does not always translate to provisions at the community level for appropriate supportive housing for adults with FASD. Currently in the north east region, where do adults living with FASD access housing?
What Happens in the Absence of Appropriate Housing?

Based on interviews with current service providers and agencies in the region it appears that supportive housing specific for these adults is very limited and in some communities, non-existent. Lakeland Centre for FASD Adult Support Coordinator Final Evaluation 2004-2007 identified a lack of supportive resources for Adults with FASD in the Lakeland region and explained that current resources for adults with disabilities were not always useful or appropriate for adults with FASD (Stonehoker, D., 2007). This evaluation report also states that FASD clients experience, “significant barriers to accessing services that may be appropriate for them for any number of reasons.”

Typical barriers to these services include:

...personal issues that make FASD clients difficult to work with—past criminal experiences and incarcerations, volatile outbursts, addictions, history of non-compliance, or not following through with and requirements...” (Ibid, 2007)

Adults living with FASD also face challenges within the systems they need to work with in the search for any housing. Scenarios they face can include:

- a lack of understanding of behaviours presented by those with FASD by the service providers;
- stereotypes and fears of those with FASD;
- cultural biases;
- the revolving door of service agencies, new workers assigned and the exhaustion on the part of the client to have to tell their story over again each time they are referred to a different agency or worker;
- no relevance or substance to the action plans or recommendations by service providers that is applicable to some adults with FASD (i.e. given an application process for Social Housing that won’t meet their needs or is beyond their capacity to complete);
• lack of flexibility for services for this population or the “one size fits all with disabilities” approach;

• difficulties in following through with supports for this population due to secondary disabilities— (homeless, drug/alcohol issues, underemployed, school disruptions in early life, victims of violence).

A reality for many adolescents and adults with FASD is often substandard housing with intermittent or chronic homelessness. The Alliance to End Homelessness defines what many of these adults face:

...as living on the streets, staying in a shelter, living in places not meant for human habitation (such as cars), or “couch surfing”—moving continuously between the homes of friends, family or strangers.”

One alternative for parents or caregivers of affected individuals to meet the housing needs of these adult is to purchase a second residence. This is a costly and stressful means of providing alternative housing independent from the family home, where much of the financial and other supports for the individual rest with extended family. This alternate housing can be a mobile home, townhouse, apartment or basements suite, but it rarely offers comprehensive, multi-disciplinary, interdependent or on-site support for the adult.

Adults with FASD can be overwhelmed or oblivious to the necessities of budgeting, shopping, household maintenance, social relationships and boundaries, and other skills needed for maintaining and keeping successful housing. Social isolation, lack of direction for daily living tasks, minimal monitoring and mentoring and frequent breakdowns in their living accommodations are common. There are countless stories of immediate family members left dealing with unpaid rent or utility bills, costs of other moves and assisting with crises on a regular basis when there are inadequate supports.

A report by J. David Hulchanski (2000) on homeless individuals speaks to those who are “inadequately housed”. This certainly captures many adults with FASD who by definition may not be classified as being homeless; the prevalence or actual numbers of
adults with FASD who are counted as homeless are uncounted because of the difficulty in identifying those who are living in substandard, inadequate housing or being supported by burned out families or caregivers. The report goes on to state:

“Not all people who have their own place to live are adequately housed. People have the human right to adequate housing. All Societies have the obligation to make progress on the adequate housing of all people. Being inadequately housed, therefore, is not the same as being homeless, but it can lead to being at risk of houselessness.”

In a 2004 housing study in Edmonton, housing preferences for homeless individuals were identified. Although the study was not specific to the adult FASD population, it did capture a common need among the homeless: “There is clearly a preference in all homeless groups for basic, independent housing with financial and other supports, both in the short term and the long term.” (Gardiner, H., Cairns, K. 2004 Edmonton Joint Planning Committee on Housing. Summary Report, 2004.)

It should be noted that rural or small communities are not immune to inadequate housing. The optics of homeless individuals, particularly those who are dealing with addictions or a dual-diagnosis, is often seen as an issue mainly centered in larger urban areas, such as Edmonton or Calgary and that it is non existent or not as prevalent in smaller communities. Factors that could influence the non-reported numbers of adults needing supportive housing in smaller, rural areas could be related to fewer numbers of emergency, short term supportive housing resources at a rural level, along with increased local family and community knowledge of individual needs of those with FASD.
Overview of Current Housing Resources in the Lakeland Region

Prior to looking at new or innovative models of supportive housing for adults with FASD, it is important to have some background on current housing resources and models of supportive housing operating at the local level. Awareness of current resources, understanding the gaps in services throughout an individual’s lifespan, and examining models that are working well can assist those looking at developing supportive housing models and strategies for this population of adults.

Persons with Developmental Disabilities (PDD) in north east Alberta contracts with Catholic Social Services (Bonnyville/Cold Lake regions), Dove Centre and WJS Alberta to provide residential, supportive Independent Living Program services and life-skills, employment support for adults with disabilities. The Supported Independent Living Program serves adults with development disabilities who live in their own home and require supports; the Approved Home Program matches individuals with approved proprietors in the community. WJS has seven shared living or group homes in the service region and also provides individualized supports in the clients’ homes, workplace or community. Services are dependent on clients meeting PDD criterion (www.ne-pdd.org).

Many adults with FASD are not able to meet PDD criterion for services. If they do qualify, opportunities for services may not be realized due to the inherent nature of the process prospective clients need to go through to access the supports. In many cases these adults will not understand or even be aware of the avenues to service access or application process and may not have the capacity to complete the necessary paperwork, make or keep appointments without guidance or follow through with planning in the absence of ongoing supports prior to the PDD approval process.

The need for assertive outreach and alternative options for housing are needed to assist those who are not aware of available formal or informal supports for housing and do not have a support network of family or others to help them access housing options. For many adults with FASD who are homeless or at-risk- being homeless, intervention or
options for housing must be brought to them through assertive outreach. The presence of barriers to accessing housing will be discussed in more detail further in the report

**Catholic Social Services**

Catholic Social Services (CSS) provides and manages resources within the Bonnyville-Cold Lake region for adults with disabilities, which can include those with FASD and is one example of PDD funded supports in the area. Presently this service provider oversees six residential resources located in Bonnyville and one located in Cold Lake. Included is one larger group living home that can accommodate six adults; 4 smaller group living homes that can accommodate 3 – 4 adults with disabilities; one group living home in Cold Lake with a 3 – 4 resident capacity, and a one -level,5 unit, semi-independent apartment complex that has separate, independent units located in Bonnyville.

The 5 -unit semi-independent resource is owned by the Bonnyville Affordable Housing Association, but is managed by CSS. The Supported Independent Living Program, funded by PDD, provides supports for residents in the group care homes and apartment; therefore it is a criterion for all residents to be eligible for PDD services. The age range of clients served are between 25 years – 80 years old; the range of disabilities also ranges from total 24 hour care and supervision to those who might receive a few hours /week of independent living supports from their assigned worker.

The smaller group living homes in both communities are rental houses, which are usually found by CSS staff. Tacey Murphy, a program manager with CSS in Bonnyville states there is an advantage in developing strong community contacts and having good knowledge of resources in the region. Building rapport and relationships with various landlords in the local area are invaluable in locating suitable rental housing for these adults.

There is a screening process to match the adults living together, with personality and interest questionnaires taken into account. Each individual has a choice as to whether they will live in the rental accommodation. The staffing is shift-staffing, rather than a

As explained by Tacey, there are demographic differences between Cold Lake and Bonnyville and these differences have some influence on housing availability, cost of rental accommodation and differences between service delivery time-frames for clients in the two communities. Bonnyville is the location for many established oil and gas industry businesses and for the most part, has a population base that is multi-generational and less transient than in Cold Lake. It was noted that the clients that CSS serves in Bonnyville tend to be longer-term than those they have in Cold Lake resources. Both communities deal with housing shortages.

The residential resources operated and managed by CSS are not specific to adults with FASD however they do have adults with this disability that utilize their resources. Again, these individuals need to be eligible for PDD services before they can access any of the housing options.

The five-unit semi-independent housing building in Bonnyville was built to be inclusive for those with disabilities. Each individual unit has a separate bathroom and kitchen-living space, and there is a common area where group social events, meals, entertainment and recreation activities can take place. Support resources are not on site 24-7, but rather are in place for each individual resident through their PDD individual support plan. This support is dependent on each resident's particular needs. According to Tacey, “one of the greatest successes is keeping a roof over their heads and for the residents to have the security of not being moved or evicted from one month to the next” (personal communication, Jan. 15, 2009). For adults living in these units and who are affected by FASD, CSS sees success and a positive response to the support offered to them as tenants. The long term relationships and education building that is established within the community has allowed some grace to be shown to the tenants. If these individuals were living in a regular rental arrangement, where other residents or landlord might not have an understanding of the secondary disabilities of an adult with FASD, the challenges that come with independent living could be
compounded with complaints and evictions that ultimately lead to the homeless cycle. In this semi-independent resource, CSS acts as a buffer for the landlord, which is Bonnyville Affordable Housing. In scenarios that could lead to crises, frustration and be cause for eviction, CSS has implemented plans to diffuse and deal with certain issues that are fairly commonplace and predictable with some of their tenants with FASD.

Some examples are when tenants inadvertently or otherwise set off the fire alarm (CSS has good communication with the local fire department) or when they misplace or lose their apartment keys on a regular basis (one of the CSS group homes across the street always has replacement or extra keys available 24-7). There are other times when CSS is able to assist the client with minor repairs or maintenance which could otherwise be overlooked or neglected in other rentals. With knowledge that these scenarios involve residents who may not have a strong sense of cause and affect, face deficits with executive functioning and abstract reasoning and having a landlord that knows their actions are not intentional or malicious, conflicts and crises can be anticipated and averted.

The common area in this 5-unit resource also provides a space for social interaction and group activities, both of which can alleviate some of the isolation and loneliness that are common in unsupported environments. For many of these adults, providing a safe, adequate physical space does not always meet the need for positive social interactions or the ability to provide support for meaningful daily routines or activities. If they are not employed, participating as a volunteer or have other perceived relevance of their use of time, many of the issues relating to addictions, justice involvement, inappropriate social relationships, mental health or health management problems can quickly fill their time.

**Cold Lake Affordable Housing Society**

Cold Lake Affordable Housing Society (CLAHS) facilitates the provision of affordable, adequate and accessible housing for the Cold Lake region [www.clahs.org](http://www.clahs.org). A current project is being developed that will see an additional 32 mixed residential units available for low – moderate income levels. Eight of the 32 units will be leased to the Dr.
Margaret Savage Crisis Centre and will provide up to 12 months of secure, affordable housing for women and their children who are leaving a violent environment. The Society will own the building, but will contract a property manager. Criterion for rentals in the building will be income-based, providing a criminal record and background checks. There are no supports provided to the tenants, other than supports or training for the eight units designated for the Dr. Margaret Savage Crisis centre clients.

CLAHS does not have a mandate to provide social housing specific to adults with FASD or other disabilities, as their foremost goal is to provide affordable housing to those in need. The lack of specific social housing projects or supportive housing by this Society does not equate or indicate a lack of understanding by their staff for the housing needs of adults with a life-long disability, such as FASD. Similar affordable housing groups are found in Bonnyville, St.Paul and developing in Lac La Biche.

**Lakeland Lodge and Housing Foundation**

This group has mandates of social housing and facilitates the rent subsidy program for eligible clients living in Bonnyville and Cold Lake. Currently, there is a waitlist of between 20 – 23 for social housing in Cold Lake. Criterion for social housing is based on income level, with the majority of tenants being eligible for the Assured Income Support for Handicapped (AISH) eligible. Prior to accepting an applicant and offering a tenancy agreement, there is an application process, interviews with family members, references checked and income criterion forms completed. It was stressed that the this particular social housing resource is affordable housing for those individuals who can manage independently and can function on their own, without being dependent on day to day supports. No ongoing, onsite supportive assistance is provided to the tenants. Presently in Cold Lake there are 12 social housing units and none currently located in Bonnyville.

The rent subsidy program provides assistance to those who would qualify for social housing, but have managed to secure a rental accommodation on their own. An example would be a single, AISH qualified client, who is entitled to $255.00/month for accommodation/rental allowance. If the rental rate is $1000.00/month, then the
difference between their AISH entitlement and the actual rental cost can be eligible for the rent subsidy. In Cold Lake, there are currently 15 low income individuals receiving rent subsidy, with the majority being on AISH. As with the Cold Lake Affordable Housing Society, this foundation sees a gap in emergency, transitional or supportive housing for adults with disabilities, including those with FASD.
Challenges and Opportunities for Supported Housing Models for Adults

Prior to any discussion of affordable, supportive housing models for adults affected by FASD, it is important to look at the fit between the individual and the supports being offered, as well as understanding the variances in behavioural symptoms that exist with those with an invisible disability. Most successful projects or supported housing initiatives have the underlying premise of respecting each individual’s right to dignity, privacy, a safe environment, involvement in the housing community, an active participant in decision making and other quality of life topics. Affordable housing is not just about providing a building to house people; it is about the people who live there.

When dealing with supportive housing for adults with disabilities, specifically those with FASD, there are some core value-based questions that can affect many issues that face this population.

Some of these issues query opposite or opposing ends of spectrums of interventions, such as inclusive vs. integrated housing being the best fit for adults with FASD; harm reduction models of intervention vs. providing services when client is clean or sober for a pre-requisite period of time; goal of providing life-long supports or accommodations for individuals vs. providing supports that will lead to independence and assimilation into mainstream society. When examining the responses to core values and its impact on housing service delivery models for adults with FASD it is paramount for support agencies and those mandated to provide housing to have a solid understanding of the disability and how prenatal alcohol exposure can affect the central nervous system. They should also have some knowledge around the ramifications of brain-based behaviour and development of secondary disabilities for those affected.

One cannot assume that adults who lack adequate or supportive housing will be proactive in accessing these appropriate resources. For many adults with FASD, their experiences with finding and maintaining adequate housing has been less than
desirable or non-existent. One alternative that has been suggested for adults with severe addictions and/or mental illnesses is low barrier housing.

While this model does not specifically serve only adults with FASD, it is understood that many adults with FASD suffer from addiction and mental health issues.

**Low barrier housing** (most often transitional with a strong harm reduction philosophy) has recently emerged as a housing and support option for people with severe addictions and/or Mental Illness (SAMI). The low barrier housing model recognizes that the SAMI population faces a wide range of challenges related to housing including locating accommodations, securing a damage deposit, signing a lease or simply producing identification (Patterson, M., Somers, J., McIntosh, K., Shiell, A., Frankish, C.J. 2008)

Inherent values in all models of housing supports for adults with FASD should include those that encourage community engagement and stakeholder involvement, which is necessary for long term success and sustainability. These stakeholders can include the private sector, not-for profit organizations, faith-based groups, and certainly should involve those affected by this disability, including those adults affected and their caregivers. According to the PDD Aboriginal Policy Framework, one of PDD’s guiding principles describes partnerships within a framework of community inclusion for services for Alberta’s aboriginal population living with developmental disabilities. The partnerships and stakeholder involvement cited below is relevant for any adults with disabilities.

**Optimal results will be achieved through a range of partnerships, between PDD, at the Ministry and Community board levels, and entities such as First Nations/Aboriginal Groups, federal and provincial government Ministries, local Authorities, and service providers** (www.pdd.org/docs/prov/AboriginalFramework2006.pdf)
Building relationships with stakeholders in the community can lead to less fragmentation of services and encourages a multi-disciplinary model of services.
Range of Service Models

The complex housing needs of these adults cannot be addressed with a singular one-size-fits-all response, but rather needs to look at the effectiveness of a range of housing models. It is important for criterion to not exclude those adults who may not have a formal FASD diagnosis, but who are certainly affected and need life-long supports to maintain appropriate housing. For many adults who have been affected by prenatal alcohol exposure, a medical diagnosis is not the norm and for them the link between supportive services being provided when they lack a formal diagnosis has been absent.

Hopefully, with new provincial FASD initiatives and the Alberta Cross Ministry FASD Service Networks, the infusion of sustainable dollars to support expanded diagnosis and continuum of care for both children and adults will provide less roadblocks and barriers for adults living with FASD.

There is research that indicates there are positive outcomes when individuals understand how they were affected by FASD. Being aware of and understanding why certain learning styles are present and being able to access support for learning accommodations for those with an organic brain injury can increase self-esteem and help them make sense of their world (Rutman, D., La Berge, C., Wheway, and D. 2002).

Outreach—foundations for stability

Agencies and service providers should be knowledgeable about the difficulties and challenges these adults face when offering housing choices for adults with FASD. Some of these challenges are behaviour-based issues and can be disruptive in the context of lack of housing supports. Strategies that can adapt and make accommodations, encourage self-control and esteem in the clients, and increase prevention of secondary disabilities are worthwhile endeavours of housing supports. These strategies are best implemented before any conflicts arise and when disputes and issues can be averted or anticipated. An expectation from most landlords is tenants use their better judgement and decision making skills based on social norms or
unspoken rules. Some examples of landlord expectations are: respecting others’ personal space and boundaries; appropriateness of guests allowed in the building; paying your rent or utilities on time; being responsible for your physical space and acting within other acceptable societal expectations; maintaining a certain level of housekeeping and maintenance standard. These expected behaviours and actions are difficult to achieve when adults with FASD are not adequately supported or lack any guidance or intervention resources that assist with daily living skills. For many supported housing projects, having on-site support makes the difference of preventing homelessness. The grass-roots or foundation to any supportive housing planning or placements is often dependent on assertive outreach programs which pro-actively seek out individuals in need, rather than the client initiating the services. While this outreach service may not be the mandate or responsibility of organizations such as PDD, it can dovetail and complement PDD programs that support adults with FASD. There are initiatives that provide outreach workers for those at risk of being homeless and for those who may need stabilizing and advocacy prior to placement in supportive housing.

British Columbia Housing has partnered with community agencies to provide connections with homeless individuals. This client-centred approach sees,

“...housing staff work in conjunction with community providers to engage individuals...and link them to appropriate services and housing. Outreach workers undertake a wide range of support activities:

*Address immediate physical and safety needs, such as food, warm clothing and a place to stay;

*Connect people with housing and income support, including making and accompanying them to appointments;

*Provide links to other support services, such as life skills training, personal health or household and financial management;

*act as a landlord liaison. (www.bchousing.org)
In north east Alberta, there are agencies that have capacity and knowledge of working with adult with FASD or who have the mandates of providing outreach services to this population. The agencies or other groups that provide ground-level supports could be stakeholders and partners with PDD programming for those adults having difficulty securing and maintaining appropriate housing due to secondary disabilities. As mentioned earlier, housing provides necessary stability prior to other supports being offered.
Transitioning to Adulthood—Housing needs

When youth affected by pre-natal alcohol exposure reach the age of majority (age 18 years in Alberta), the notion of them being able to access suitable housing and eventually become independent and function day to day with no supports is unrealistic for many. This expectation can also set them up for lifelong disappointments of facing revolving doors of temporary housing, homelessness, or placing the responsibility on other adult caregivers. Agencies that provide services to youth with a disabilities, particularly when the youth is a ward of the government, are responsible for developing transition plans to prior to the youth reaching adulthood. The goals of case management or planning should look at provisions for housing and plans for support into adulthood, and assurance that levels of support will not be temporary or fleeting for those needing continuation of services past their discharge from care. When putting the discharge plan in place, logistics such as the young adult’s financial limitations, wait times for housing or availability of resources in their community, and criterion for accessing adequate housing. All of these issues can influence future standards of supports for these youth. There are existing assumptions around young adults with FASD and their ability to function independently after the age of 18. An unrealistic picture or misunderstanding of the disability and focusing only on the behaviour of the individual without the benefit of understanding the motives behind the behaviour can actually cause more harm. Inappropriate referrals may be made to employment or job readiness courses, cognitive or behavioural models for working on issues, or short-term or emergency housing. Many of these well-intended referrals to programs have the an assumption that adults with invisible disabilities will be able to function independently as long as they stay out of trouble and try hard. This model is skewed, as it is dependent on the young adult having the ability to make changes in their adaptive functioning and does not take into account any central nervous system damage, knowledge or accommodations that would be helpful to assist them with daily tasks and the permanency of the life-long challenges that they will face. When case managers who are responsible for youth affected by FASD begin to question and search for supported or other optional housing that might provide these resources, appropriate models can
be developed in partnership with agencies responsible for services for those with disabilities.

Case planning with youth who are approaching adulthood should look at their housing needs and strategies for support long before the age of majority is reached. For some youth, supported housing may be necessary prior to their 18th birthday. It is hoped that young adults will remain out of the scope of justice and legal systems, poverty or homelessness, and that agencies providing housing supports are pro-active and have mandates to begin planning prior to adulthood.

Communities should be aware of their demographics and the pending number of possible diagnosed children and youth with FASD, know where these youth are currently living, and examine the options that are available for them in later years. LCFASD provides FASD diagnostic services for youth and adults in north east Alberta communities and their capacity for diagnosis increases each year due to program expansions, provincial funding availability and increased provincial targets for diagnosis of youth and adults.

Being aware of the number of adults in the region that meet PDD criterion and also have FASD diagnosis is timely when discussing supportive housing for the region. In most communities, there is also an understanding that no one agency or group is entirely responsible for providing the many levels of care and support needed for adults with FASD.
Provincial Models of Collaborative Housing Responses

The standard for FASD diagnosis in Canada outlines the use of multi-disciplinary diagnostic teams who bring information to the diagnostic clinician, assisting with necessary background information about the client and to assist with concrete continuum of care recommendations for post-clinic follow-up (Chudley et al., 2005). Supported housing efforts also need to be seen as multi-disciplinary or collaborative in nature. In Prince George, BC the Northern Family Health Society completed a supportive housing feasibility study that looked at approaches of dealing with the housing issues for those living with FASD (August, 2007). This report states:

...a supported housing framework offers the opportunity for a housing strategy to emerge from the building of capacity of resources that already exist in the community and to offer multiple points of engagement.

The report goes on to describe the advantages of looking at present resources in the community as a beginning focal point and to set sights on building new projects or housing structures later if needed.

The BC Provincial Homelessness Initiative (PHI) through BC Housing allocates funding to developments that integrate subsidized housing with supports services for people who are homeless or at risk of being homeless; those with mental illnesses and physical disabilities; those with drug and alcohol addictions; aboriginal peoples; youth; and women fleeing abusive relationships. Other towns and cities in BC have developed the concept of converting single occupancy hotels in downtown core areas for affordable housing, with a spectrum of multi-disciplinary supports available to residents. There is 24-hour security, treatment and support options including addiction, medical and mental health resources.

The premise is to provide stable housing and then begin to deal with some of the listed issues. (www.bchousing.org/programs/homelessness).
Alberta’s Community Based Homeless Initiatives partner with other levels of government, municipal organizations, private and not-for-profit housing sectors to provide effective, long-term housing solutions to seven major cities and communities in Alberta. Some of these initiatives could be developed in other areas of Alberta, such as the north east region, as there are already established sustainable housing societies and Lakeland Centre for FASD, which has a broad knowledge base regarding adults with FASD. In 2007, Wood Buffalo region developed a 3 year plan to address some of the assets and gaps in regional housing (Stubbs, T. et al., 2007). Three principles that guided implementation of the report were:

* to ensure the safety and security of individuals and families (provide food, clothing, safe shelter)

* to provide a continuum of care approach

* work with other community stakeholders to achieve partnership between sectors and agencies

Communities that are beginning strategic planning and discussions about supporting adults who typically do not fit the criterion for many housing resources, such as adults with FASD, need to develop guidelines that will assist with the parameters of housing issues for this population.

In Red Deer, Alberta, the Canada-Alberta Affordable Housing Program provides funding for The Buffalo Project. This housing initiative is a partnership between the not-for-profit Potter’s Hand Housing Society, and Canadian Mental Health and has been operational for about one year. It is based on a Housing First philosophy, a response to homelessness which initially began in New York City as a means of getting people off the street and into housing as a first priority.

The Buffalo Project follows the goals of this philosophy by providing a low- barrier, harm reduction model for tenants who are cognitively impaired, have an acquired brain injury, and certainly includes many who are living with FASD. According to Sheila Dodge, Housing Manager with the Housing First program in Red Deer, there is a wide
spectrum of disabilities and needs amongst the tenants, with most dealing with addictions and mental illnesses. She states around 95% have addiction issues and around 80% need support in dealing with mental health issues.

Those with the most severe needs are at the top of their list; there are no cognitive level or alcohol/drug free criterion for admissions before accessing the housing (Personal Communication, Sheila Dodge, January 22, 2009). This low or no-barrier approach ensures that those who are most needy are provided housing and then supported based on individual assessments.

The Housing First premise is to build relationships with the tenants and provide a collaborative approach to care and support. Support from onsite, front-line tenancy support workers is available 24 hours a day, seven days a week. These workers are experienced with addiction and mental health issues and provide a full continuum of support to adults who have a range of secondary disabilities and who have experienced chronic homelessness. There is also a monthly psychiatric clinic onsite for tenants. As Canadian Mental Health is an approved PDD service provider, this agency employs the individual workers for those tenants who are eligible for PDD services. The Buffalo Project is located at an old downtown hotel in Red Deer and is a work-in-progress, with ongoing renovations to the units. Currently, there are 25 independent bachelor suites, with the potential for a total of 40 suites. The Potter’s Hand Society owns the building and acts as the landlord.

The most current Buffalo project that is also onsite is a newly developed vocational training program available for eligible tenants. This Hospitality Industry Training Program provides targeted training in the service industry. This opportunity is managed for positive completion by participants, increasing success by having the program operate onsite in the building where the residents reside. Instructors and program coordinators have a level of understanding regarding students’ the strengths and limitations. Upon completion of the program, there are employment opportunities for participants within The Buffalo Project by working in food preparation for the other tenants or with other appropriate employers.
Opportunities for North East Region of Alberta

There is much potential and a range of opportunities for regions throughout Alberta to explore housing partnerships with agencies, government bodies or funded agencies, not-for-profit or grassroots organizations and to begin discussions around a wrap-around supportive housing model for adults with FASD. The business community, community colleges, Municipal Affairs and other interested stakeholders are all part of the solution as regions direct attention to building capacity for social and supportive housing for adults with a disability. A supported housing program that can also accommodate vocational or other training and serves the needs of both tenants and the community is a win-win for both parties.

Much can be learned from examining other projects that are operational and often began from the same place as most—to provide appropriate, sustainable housing with supports for individuals needing mentorship, companionship, life-skills and other direction, respect and an interdependent model of care and shelter. It is recognized that many of these individuals will require permanent, life-long supports.

The starting point for any groups investigating housing solutions for these adults is to examine current community supports and assets and to have a thorough knowledge of demographics and the population that requires these supportive housing services. Knowing the numbers of youth and adults diagnosed with FASD in the region; the numbers of youth transitioning to adulthood and who are under a current model of care by government bodies; and the communities’ capacity for emergency, short term and long term housing for adults with a disability are all important statistics that will drive the need for certain resources. Not all communities, even within a geographic region, will have the same needs for services. Stakeholder and other community support will also dictate the level of services that can be developed.

Partners and stakeholders sitting at the table during discussions of supported housing should be multi-disciplinary in nature, due to the variance in needs of this adult population. Agencies that are responsible for post-release or discharge planning from correctional facilities, hospitals and addiction resources are essential continuum of care
planners that can offer much in the way of long-term supports needed to encourage stable housing rather than the revolving door back to the jails, treatment centres or the streets. As is the case with most collaborative planning, there needs to be an established body identified to take the lead and focus on the integration of supportive housing services for those with this disability. Measurement of success for housing will be the number of clients living in suitable resources. This will take a concerted effort by all agencies working together. For the most part, this population of adults may not proactively seek out housing resources, so the system needs to accommodate this.

Potential communities that are ready to develop supported housing strategies should be prepared for the stigmas attached to the homeless and housing stereotypes that are prevalent for those who live in supported housing and have a disability. The tolerance level or lack of can become apparent when neighbourhoods are the site for planned housing.

Local and regional education and knowledge are key components of any supported community housing plans. PDD and other agencies are excellent resources for encouraging community awareness and participation to lobby government and educate others regarding the housing dilemma.

Municipalities and other agencies can learn helpful best practices and lessons from other successful housing projects in the province. Examination of regulatory solutions to housing, such as building codes, staffing, hotel conversions to individual units, secondary suites in homes, streamlining building permits, zoning for housing, and accessing agricultural land outside city limits can be instrumental in providing creative options for improving affordability, accessibility and success for supportive housing for adults with FASD.

Edmonton’s Jasper Place Health and Wellness Centre received funding for permanent housing programs for the most vulnerable in the city. Certain processes are put into place for residents in this program. The finances of the tenants are overseen by the centre’s staff; they agree to regular follow up visits with centre staff and are asked to not
have their apartment act as a drop-in for their friends. Jasper Place also adopts the Housing First Philosophy (Zabjek, A. Edmonton Journal, Jan. 27, 2009).

“The Centre has 10 housing support workers who typically have 20 clients to manage every week ...but before support workers can worry about keeping a client in an apartment, they have to find them one. That involves tirelessly canvassing apartment listings and building relationships with landlords. Landlords might be willing to take a less-than-ideal rental candidate if they know...staffs are there to backstop any problems” (Edmonton Journal, Jan. 27, 2009).

If a permanent building is not available for supported housing, support workers could potentially build relationships with understanding landlords, with the assurance that adequate supports and resources are ongoing for their tenants. This solution might prove difficult in geographic areas that have a very low vacancy rate and expensive rental costs. Another indicator of success is often the difference of the location of supportive housing. When some tenants move to housing that is outside their usual location, the disassociation from old contacts can encourage positive mentorship and treatment potential for drugs and alcohol treatment.

A program that is funded by Canadian Mortgage and Housing Corporation and delivered by the Federation of Canadian Municipalities is ACT (Affordability and Choice Today). This program provides moderate grants for informing others on housing solutions or funding to host workshops to discuss innovative and successful models of housing. It also provides an excellent resource for regulatory solutions to a variety of housing solutions (www.actprogram.com).

Perhaps one of the strongest assets for the northeast region of Alberta with regards to resources for adults with FASD is the Lakeland Centre for FASD and the partnerships and programming the centre has developed in the communities within its service region. Partnerships with agencies that are able to provide expertise in training, programming, and delivery of services for a specific population are valuable stakeholders in any discussion of housing provisions in the region. LCFASD has developed relationships
with various agencies in the region, including PDD, and has in-kind contribution and participation on their youth and adult FASD diagnostic clinics. The Northeast region is the locale for many provincial pilot initiatives and a newly developed Provincial FASD Network, which provides mentorship for vulnerable women of child-bearing years, FASD diagnostic services for youth and adults and a continuum of care, support follow up for those affected. There are many other agencies and organizations in the region that will be pivotal in discussing housing for adults with FASD.
Conclusion

The intent of this report is to shed light on the housing needs of the most vulnerable in our society, including those who often are not aware of their need for supportive, safe and affordable housing that will serve their life-long needs. Development of housing for adults with FASD is navigating unchartered waters for many organizations; however there appears to be a will from all levels of government, agencies, and community to look at positive solutions to homelessness. Increasingly, we are seeing Society’s expectation for housing that provides more than a short-term warehouse approach, with little sustainability. The short term model ultimately leads to the increase in homelessness and secondary disabilities seen in so many adults with FASD. The shift to low-barrier, housing-first strategies that offer life-long supports makes economic sense and allows communities to develop resources that match their unique needs.

Supportive housing for adults with FASD requires stakeholder involvement with a range of community partners. The northeast region of the province, served by PDD, has a wide range of supportive housing models to examine both within and outside the region. The goal is to match the appropriate model to the needs of their clients. It is recognized that solutions will not be created over a short period of time and that quick-fixes rarely last the test of time for adults that require life-long supports.

Dialogue and discussions around housing for those living with FASD must be ongoing and involve all agencies responsible for provision of this most basic need. Creative options, including hotel conversions, location of interdependent housing and various levels of support and entry points for tenants must be explored as alternatives. Training for staff is essential when working and coming alongside adults with FASD, as conventional standards of intervention may not be always appropriate with this population. Ongoing evaluations and having an agency directly responsible for steering stakeholder response to homelessness is important to keep the goals on track to and for plans to not get lost or misguided over time. There are numerous models of supportive housing to evaluate across the country; choosing a direction that will serve the needs of PDD’s north east region might serve as a best practices approach for other areas of the province.
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Zabjek, A.  The Simple Solution: Just Give Them a Home. Edmonton Journal: January 27, 2009, pp. 1, 4

www.actprogram.com

www.bchousing.org/programs/homeless_outreach_Program

www.clahs.org

### Alberta FASD Diagnostic Clinics

**Alberta Children's Hospital FASD Diagnostic Clinic**  
Contact: Shirley Wormsbecker  
1820 Richmond Road SW  
Calgary, AB  
403.943.7231

**Bosco Homes – Society for Children and Adolescents*  
Contact: Central Intake Coordinator, Calvin Woods**  
6770 129 Ave  
Edmonton, AB  
T5C 1B7  
780.440.0708

**Canadian FASD Diagnostic and Training Centre Ltd.**  
Contact: Viki Jacob, Team Program Facilitator  
Box 381  
Redwater, AB  
T0A 2W0  
780.942.2819

**Centerpoint Young Offender Program**  
Contact: Dr. Roy Frenzel  
Suite 701, 10242 105 Street  
Edmonton, AB  
T5J 3L5  
780.428.4524  
*275

**East Central Health FASD Clinic**  
Contact: Dr. Alyson Lavers  
Camrose Public Health, ECHA, 5510 46 Ave  
Camrose, AB  
T4V 4P8  
780.679.2980

**FASD Program – Accredited Supportive Living Society**  
Contact: FASD Program Coordinator  
Box 680  
Grimshaw, AB  
T0H 1W0  
780.332.4183  
*112

**Glenrose Rehabilitation Hospital – FASD Clinical Services**  
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Edmonton, AB  
T5G 0B7  
780.735.7999 ext. 15328
<table>
<thead>
<tr>
<th>Organization</th>
<th>Contact</th>
<th>Address</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lakeland Centre for Fetal Alcohol Spectrum Disorder</td>
<td>Donna Fries, Coordinator</td>
<td>Box 479, Cold Lake, AB T9M 1P1</td>
<td>780.594.9905</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Toll Free: 1.877.594.5454</td>
</tr>
<tr>
<td>Medigene Services Inc. – FAS Diagnostic Clinic</td>
<td></td>
<td>Foothills Professional Building, Suite 110, 1020 – 29 St. NW Calgary, AB T2N 4L7</td>
<td>403.571.0450</td>
</tr>
<tr>
<td>Northern Association for FASD</td>
<td>Charlene McKay, FASD Coordinator</td>
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<tr>
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</tr>
<tr>
<td>Regional FASD Program, A Division of Bridges Family Programs</td>
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<td>403.526.7473</td>
</tr>
<tr>
<td>Renfrew FASD Diagnostic Consultation and Intervention Clinic</td>
<td>Sherry Dow, Intake, FASD Services</td>
<td>2050 21 Street NE, Calgary, AB T2E 6S5</td>
<td>403.225.2144</td>
</tr>
<tr>
<td>Renfrew Schools</td>
<td>Sherry Dow, Intake, FASD Services</td>
<td>2050 21 Street NE, Calgary, AB T2E 6S5</td>
<td>403.225.2144</td>
</tr>
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</table>

Updated: July 2006
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,
© Copyright: Connections: Serving Adolescents and Adults with FASD
Email: info@fasdconnections.ca
Web: www.fasdconnections.ca
"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.
A heartfelt thank you is made to Brewers of Canada who provided funding to bring all participants together to participate in this two-day forum. Without their help, this forum and the resulting “Fighting for a Future” report would not have been possible.
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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:

<table>
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<th>Sample</th>
<th>Disrupted Schooling (Percentage)</th>
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<tr>
<td>Females with PFAS/ARND (ages 21 – 51)</td>
<td>76%</td>
</tr>
<tr>
<td>Males with PFAS/ARND (ages 12 – 20)</td>
<td>76%</td>
</tr>
<tr>
<td>Males with PFAS/ARND (ages 21 – 51)</td>
<td>70%</td>
</tr>
<tr>
<td>Males with FAS (ages 12 – 20)</td>
<td>70%</td>
</tr>
<tr>
<td>Females with FAS (ages 21 – 51)</td>
<td>52%</td>
</tr>
<tr>
<td>Females with PFAS/ARND (ages 12 – 20)</td>
<td>50%</td>
</tr>
<tr>
<td>Males with FAS (ages 21 – 51)</td>
<td>43%</td>
</tr>
<tr>
<td>Females with FAS (ages 12 – 20)</td>
<td>30%</td>
</tr>
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</table>

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:

<table>
<thead>
<tr>
<th>Mental Health Diagnosis</th>
<th>Percentage of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>52%</td>
</tr>
<tr>
<td>Continuing ADHD problems</td>
<td>Over 40%</td>
</tr>
<tr>
<td>Suicide threats</td>
<td>43%</td>
</tr>
<tr>
<td>Panic attacks</td>
<td>33%</td>
</tr>
<tr>
<td>Psychosis (hearing voices / seeing visions)</td>
<td>29%</td>
</tr>
<tr>
<td>Suicide attempts</td>
<td>23%</td>
</tr>
</tbody>
</table>

- 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
- 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:

<table>
<thead>
<tr>
<th>Sample</th>
<th>Drug &amp; Alcohol Problems (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females with PFAS/ARND (aged 21 – 51)</td>
<td>70%</td>
</tr>
<tr>
<td>Males with PFAS/ARND (aged 21 – 51)</td>
<td>54%</td>
</tr>
<tr>
<td>Females with PFAS/ARND (aged 12 – 20)</td>
<td>38%</td>
</tr>
<tr>
<td>Females with FAS (aged 21 – 51)</td>
<td>37%</td>
</tr>
<tr>
<td>Males with FAS (aged 12 – 20)</td>
<td>32%</td>
</tr>
<tr>
<td>Males with FAS (aged 21 – 51)</td>
<td>30%</td>
</tr>
<tr>
<td>Males with PFAS/ARND (aged 12 – 20)</td>
<td>30%</td>
</tr>
<tr>
<td>Females with FAS (aged 12 – 20)</td>
<td>4%</td>
</tr>
</tbody>
</table>

- 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:

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

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:

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

• 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, Martsolf 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:

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

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

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.
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.
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.
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. 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 45th 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 an 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 (i.e. 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.
“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 19th 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 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.
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”.\(^1\) 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”.\(^2\) 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

\(^{1}\) Merriam Webster’s Deluxe Dictionary, 10\(^{th}\) Collegiate Edition; 1998
\(^{2}\) 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”. 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)”. 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”. 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 19th birthday, everything stops. The only allowance for even limited services is for those individuals with an IQ

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1 Ibid
2 Ibid
3 Ibid
4 Ibid
5 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 and 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”)

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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6 Merriam Webster’s Deluxe Dictionary, 10th 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:

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

<table>
<thead>
<tr>
<th>ITEM</th>
<th>COST ESTIMATE PER INDIVIDUAL TO FAMILY</th>
</tr>
</thead>
<tbody>
<tr>
<td>The overage from the above</td>
<td>$279.00 per month or $3,350 per year</td>
</tr>
<tr>
<td>Eye check-ups</td>
<td>$75.00 per year</td>
</tr>
<tr>
<td>Prescription medications not covered (all brand name, non generic; any anti-inflammatory, any sleeping medication; many antibiotics; most allergy sprays and medications)</td>
<td>$800.00 per year</td>
</tr>
<tr>
<td>Non-prescription medications, melatonin, first aid supplies; antibiotic creams, cost of crutches, etc.</td>
<td>$600.00 per year</td>
</tr>
<tr>
<td>Physiotherapy, chiropractic, occupational therapy (limited to only 12 combined visits each year for all services outside doctor for PWD)</td>
<td>$50.00 per visit after 12 PWD visits; could amount to $500.00 per month for any one service</td>
</tr>
<tr>
<td>Splints, orthotics, braces, eye glasses, (replacement costs; some initial costs due to limited coverage for PWD; all costs for others)</td>
<td>$1,000 per year</td>
</tr>
<tr>
<td>Dental care for cavities, etc. over $700.00 PWD funding</td>
<td>$2,000.00 per year on average</td>
</tr>
<tr>
<td>Dental appliances and replacements (initial cost for appliance may be covered; approval process can take 6 months or longer)</td>
<td>$1,000 per year</td>
</tr>
<tr>
<td>Oral surgery (wisdom teeth)</td>
<td>$1,500.00 and up</td>
</tr>
<tr>
<td>All anesthetic costs for any outpatient surgery</td>
<td>$300.00 per occasion</td>
</tr>
<tr>
<td>Birth control</td>
<td>$ Variable, some covered – some not.</td>
</tr>
<tr>
<td>Mental health therapy utilizing a skilled therapist knowledgeable about FASD</td>
<td>$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. Note: most individuals with FASD receive no funding under RHAP or CICP</td>
</tr>
<tr>
<td>Food supplements that may be essential to health; PWD may provide $40/month with prescription; time limited</td>
<td>Between $480 and $1,000 per year for most; occasionally ranges as high as $1800</td>
</tr>
<tr>
<td>Cost of diagnosis (if required)</td>
<td>$4,000.00 one time cost</td>
</tr>
<tr>
<td>Cost of medical forms</td>
<td>$25.00 per form per occasion plus cost of the office visit</td>
</tr>
<tr>
<td>ITEM</td>
<td>COST ESTIMATE PER INDIVIDUAL TO FAMILY</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Assessments (non PWD)</td>
<td>$1,000.00 per occasion and up</td>
</tr>
<tr>
<td>Cost of PWD assessments and paperwork</td>
<td>$250.00 to $1,000.00 each re-assessment</td>
</tr>
<tr>
<td>Damage deposits (rarely, if ever, recovered; will only be provided once by MCFD; after that, they are deducted from monthly cheque)</td>
<td>$250.00 per occasion on average</td>
</tr>
<tr>
<td>Utility hookups</td>
<td>$150.00 per occasion</td>
</tr>
<tr>
<td>Cleaning costs</td>
<td>Highly variable; depending on state, and who does the cleaning; likely about $150.00 per occasion; can be much higher</td>
</tr>
<tr>
<td>Repairs (minor)</td>
<td>$50.00 - $75.00 not including labour provided by family, per occasion</td>
</tr>
<tr>
<td>Repairs (major) – electricians, plumbers, etc.</td>
<td>$250.00 per occasion</td>
</tr>
<tr>
<td>Laundry costs (laundromat)</td>
<td>$240.00 per year</td>
</tr>
<tr>
<td>Costs of moving, including eviction costs</td>
<td>$300.00 - $400.00 per occasion</td>
</tr>
<tr>
<td>Replacement of damaged, lost, stolen goods/equipment, for individual and others</td>
<td>$750.00 per year</td>
</tr>
<tr>
<td>Insurance rider costs</td>
<td>$100.00 per year</td>
</tr>
<tr>
<td>Capital costs of furniture (used, from family, etc.)</td>
<td>$1,000.00 to set up</td>
</tr>
<tr>
<td>Capital costs of household goods</td>
<td>$2,500.00 to set up</td>
</tr>
<tr>
<td>Long distance phone calls to/from parents/adult; to other agencies, companies, etc. to deal with events</td>
<td>$600.00 per year</td>
</tr>
<tr>
<td>Replacement costs for ID, bus passes, etc.</td>
<td>$200.00 per year</td>
</tr>
<tr>
<td>Legal fees (as defendant; as victim); legal aid defense will almost certainly end in jail time</td>
<td>$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</td>
</tr>
<tr>
<td>Fines, tickets (may also have used the name of another leading to fines in their names)</td>
<td>$500.00 per year</td>
</tr>
<tr>
<td>Prison visit and support costs (mileage, cost of babysitter in the home, meals, money for prison canteen account, etc.)</td>
<td>$1,000.00 per year – highly dependent on location of prison, number of visits, etc. Could be much higher</td>
</tr>
<tr>
<td>Court costs; transcripts, etc</td>
<td>$250.00 per year</td>
</tr>
<tr>
<td>Transportation costs associated with legal situations</td>
<td>$250.00 per year</td>
</tr>
<tr>
<td>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</td>
<td>$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)</td>
</tr>
<tr>
<td>ICBC imposed sanctions</td>
<td>$750 - $5,000.00 depending on circumstances</td>
</tr>
<tr>
<td>ITEM</td>
<td>COST ESTIMATE PER INDIVIDUAL TO FAMILY</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Cost of notarized documents</td>
<td>$ 25.00 per occasion</td>
</tr>
<tr>
<td>Handi-dart (door-to-door transportation for disabled adults unable to use bus service for a number of reasons; many with FASD would qualify)</td>
<td>$ 1,200.00 per year for one return trip daily Monday to Friday</td>
</tr>
<tr>
<td>Portion of vehicle costs required to continue to be accessible 24/7; insurance, maintenance, repairs</td>
<td>$1,200.00 per year – assumes vehicle is paid for</td>
</tr>
<tr>
<td>Cost of driving adult to and from to provide supervision/avoid problems – mileage</td>
<td>$1,200.00 per year</td>
</tr>
<tr>
<td>Parking (miscellaneous – meters, lots, etc., for therapy, AA meetings, appts., etc.)</td>
<td>$ 750.00 per year</td>
</tr>
<tr>
<td>Financial “bailouts” (credit cards, finance company loans, lines of credit, bills, fraud, possible drug debts)</td>
<td>Highly variable; highly expensive; usually not done; sometimes has to be</td>
</tr>
<tr>
<td>Costs of airfares, bus tickets, hotels, meals, taxi, etc. to reclaim adult kids</td>
<td>$1,000.00 per year on average</td>
</tr>
<tr>
<td>Cost of meals for adult on street</td>
<td>$ 600.00 per year</td>
</tr>
<tr>
<td>Cost of returning belongings from one location to another</td>
<td>$ 150.00 per year</td>
</tr>
<tr>
<td>Costs associated with illness/injury in child requiring parent to attend another city, etc.</td>
<td>$3,000.00 and up per occasion, depending on location (high cost airfares; short notice; plus hotels and meals)</td>
</tr>
<tr>
<td>Cigarettes</td>
<td>$ 600.00 per year</td>
</tr>
<tr>
<td>Recreation passes</td>
<td>$ 100.00 per year</td>
</tr>
<tr>
<td>Entertainment</td>
<td>$ 500.00 per year</td>
</tr>
<tr>
<td>Cost of accessing treatment (finding it, getting a person there, etc.)</td>
<td>$ 500.00 and up per occasion, depending on lost time from work, travel, location, etc.</td>
</tr>
<tr>
<td>Adult vocational services</td>
<td>$1,000.00 per year adult basic education</td>
</tr>
<tr>
<td>Vocational rehabilitation services</td>
<td>$1,000.00 and up per occasion</td>
</tr>
<tr>
<td>Vocational training courses</td>
<td>$3,000.00 per year and up</td>
</tr>
<tr>
<td>Employment supports (special shoes, clothing, tools, etc.)</td>
<td>$ 500.00 and up depending on job needs; per job placement</td>
</tr>
<tr>
<td>Cost of time spent educating employers, providing supports to them, etc.</td>
<td>Dependent on amount of time parent must take to do this</td>
</tr>
<tr>
<td>Clothing and shoes (additional); includes cost of having to re-outfit</td>
<td>$1,000.00 per year</td>
</tr>
<tr>
<td>Food</td>
<td>$1,000.00 per year</td>
</tr>
<tr>
<td>Personal care</td>
<td>$ 250.00 per year</td>
</tr>
<tr>
<td>ITEM</td>
<td>COST ESTIMATE PERSONAL TO FAMILY</td>
</tr>
<tr>
<td>------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Gifts</td>
<td>$ 200.00 per year</td>
</tr>
<tr>
<td>Support to grandchildren’s costs</td>
<td>Usually substantial costs depending on where the child is being raised; likely minimum amount is about $5,000.00 per year</td>
</tr>
<tr>
<td>Replacement of cell phones</td>
<td>$ 100.00 per occasion</td>
</tr>
<tr>
<td>Paid one-to-one worker</td>
<td>$4,800.00 per year – 5 hours per week at $20/hour</td>
</tr>
<tr>
<td>Respite care</td>
<td>Rarely ever due to lack of funds; would cost in neighbourhood of $150.00 per day and up</td>
</tr>
</tbody>
</table>
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Issues around Adult Diagnosis of FASD

Diagnosis of FASD in adults is more difficult than in children. Assessment and diagnosis of FAS or alcohol-related effects is most accurate when done between the ages of 2 and 11 years. After this time, diagnosis may not be possible or may require a skilled clinician who is experienced in adult diagnosis (Institute of Medicine, 1996). This is due to the changes that occur in the individual after puberty. Growth catch up is common and the individual’s facial morphology may change (Streissguth, 1994), both of which limit the diagnosis that can be given, as the diagnostic criteria are based on growth restrictions and facial characteristics. Even as a child, the individual may not have had obvious physical symptoms of FASD (e.g., distinctive facial characteristics) and these may be more difficult to identify in adulthood (Spohr, Willms, & Steinhausen, 2007). Often, the presenting symptoms of FASD in adults are: serious mental illness (SMI), substance abuse, conflict with the law, difficulty with employment and precarious housing (Alberta Centre for Child, Family, and Community Research, 2013).

FASD diagnosis involves the following (Public Health Agency of Canada, 2011):

- **physical examination**: involves appropriate measurements of growth, assessment of findings, and documentation of anomalies;
- **dysmorphology assessment**: can identify specific facial features related to prenatal alcohol exposure;
- **neurobehavioural assessment**: involves and evaluation of the hard and soft neurological signs, brain structure, cognition, communication, academic achievement, memory, executive functioning and abstract reasoning, and attention deficit/hyperactivity; and
- **confirmation of prenatal alcohol exposure or alcohol consumption by the mother during the pregnancy**: can be obtained through a direct interview with the mother or other sources (e.g., reliable clinical observation, reports by a reliable sources, or medical records).

Diagnosis of FASD in adults is also difficult due to a lack of resources in adult oriented service systems and historical information to support such a diagnosis may be absent or unknown (Gelb & Rutman, 2011). Only Fetal Alcohol Syndrome can be diagnosed without the confirmation of maternal alcohol consumption during pregnancy (see Appendix 1), and this information may be difficult to obtain (Fast & Conry, 2004).

Diagnosis is important. Early diagnosis is associated with the prevention of secondary disabilities (Streissguth, Barr, Kogan, & Bookstein, 1997). As the individual ages, disabilities become more difficult to manage and behaviours are less easy to change. This is made worse by the expectation of independent functioning in adulthood – individuals with FASD may not be capable of this and yet, without a diagnosis, may be unable to access necessary services and supports (Lutke & Antrobus, 2004). The longer the delay in receiving a diagnosis, the more likely adverse outcomes will take place (Streissguth et al., 2004).
Understanding FASD Dysmaturity

DYSMATURITY, developmental immaturity, is a clue to brain damage from prenatal alcohol exposure, an FASD.

HERE is an 18 year old, described in the chart below; a physically mature young adult with a functional age equivalency of a 10 year old.

NOW: Imagine a 10 year old driving a car, getting to work or class on time, managing a checkbook, keeping clean – all skills you would normally expect of someone 18 years old.

Reframing YOUR perceptions from "WON'T" to "CAN'T"