Life Span Intervention Strategies for Fetal Alcohol Spectrum Disorder:
A Literature Review

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Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university, and that to the best of my knowledge and belief it does not contain any material previously published or written by another person where due reference is not made in the text.
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Chapter One
Introduction

Aim of the Study

Fetal Alcohol Spectrum Disorder (FASD), the life-long disability caused by maternal consumption of alcohol during pregnancy, has significant potential for acquired secondary disabilities, such as disrupted schooling, substance abuse, mental health disorders, homelessness, unemployment, and difficulty with the law. This study will examine the current literature regarding Fetal Alcohol Spectrum Disorder and provide an overview of the challenges faced over the lifetime by individuals affected by this condition.

This study will explore the prevalence of FASD in society, the primary and secondary disabilities associated with prenatal exposure to alcohol, the risk factors associated with FASD, the role of diagnosis, and the challenge of caregivers and professionals to provide sufficient support. This paper will also examine educational strategies recognized by the literature as best practice interventions and accommodations for students with FASD.

The aim of this study is to provide educators and caregivers with an overview of FASD and to provide meaningful intervention strategies that may help mitigate the affects of secondary disabilities.

Problems Underlying the Study

Alcohol continues to be a widely used, legal, and socially acceptable drug. A survey by the Canadian government found that 79.3% of the population aged 15 years and older consumed alcohol in the previous year (Collin, 2006). Most people are aware of the short-term effects of alcohol: released tension, decreased inhibition, loss of fine motor
control, impaired reasoning, and memory loss (CAMH, 2008). However, society continues to have a much poorer understanding of the potentially devastating effects of alcohol consumption by pregnant women.

Fetal Alcohol Spectrum Disorder is theoretically 100% preventable. FASD is caused by prenatal exposure to alcohol and cannot occur if a pregnant woman refrains from drinking alcohol. Yet FASD continues to be recognized as one of the leading causes of preventable birth defects and developmental delays in Canada (Canadian Paediatric Society, 1997). Historical warnings about the potentially harmful effects of drinking alcohol while pregnant can be found in the Old Testament and from Greek medical philosophers (Streissguth, 1997). However, it was not until 1973 that Fetal Alcohol Syndrome was formally diagnosed (Mattson & Riley, 1997). FASD is a relatively new field of study. A recent survey measuring how well the Yukon’s justice system deals with clients who have FASD found that justice professionals knew very little about the disorder (CBC, 2008). It is clear that the public and frontline workers require more education about FASD.

Fetal Alcohol Spectrum Disorder presents significant challenges to the education system. In the Yukon Territory, which has a population of about 30,000 people, it is estimated that twenty-four children are born with FASD every year (Alton & Evensen, 2006). Many of these students will not be formally diagnosed, or possibly misdiagnosed, but all of them will go to school. Since FASD is a continuum, the scope and severity of effects will be unique to the affected individual (Lasser, 1999). Many students with FASD will not have any distinguishing physical features that make their condition easily identifiable.
Teachers need to be aware of the indicators of prenatal exposure to alcohol, especially the associated learning and social skills deficits that may be present without any physical characteristics. There is an urgent need for an increase in the amount of preservice and inservice training for teachers in the area of FASD (Burd, 2006). Teachers should be knowledgeable of the teaching methods and behavioural strategies known to help children with FASD develop to their full potential even in the absence of a formal diagnosis.

Research Questions:

1. What are the causes of FASD and how is it diagnosed?
2. What are the primary and secondary disabilities associated with FASD?
3. Does early diagnosis provide the opportunity for programming which would lessen the development of secondary disabilities?
4. What teaching strategies are considered best practice for individuals with FASD?

Research Methods

This Coursework Project will consist of a literature review of journal articles, books, and government publications relevant to Fetal Alcohol Spectrum Disorder. The multidisciplinary nature of the field of Fetal Alcohol Spectrum Disorder resulted in research being drawn from databases addressing education, law, criminology, health care, psychiatry, disability studies, occupational therapy, and psychology. Articles, books, and governmental publications between 1994 and 2008, with the exception of two background articles from 1987, were used to illustrate the lifespan of individuals with Fetal Alcohol Spectrum Disorder and to provide educational strategies currently considered best practice.
Significance of Study

Fetal Alcohol Spectrum Disorder is a life long disability caused by prenatal exposure to alcohol. Early diagnosis of FASD is vitally important to ensure that behaviours are interpreted as symptoms of an underlying disability and interventions are planned to minimize the development of secondary disabilities. Regrettably, research suggests that FASD remains significantly under-diagnosed because of a current lack of awareness or understanding of the problem (Malbin, 2004).

Alcohol consumption in the Yukon remains the highest per capita of all provinces and territories in Canada (Brewers Association of Canada, 2007). Yukon educators need to be aware of the effects of prenatal exposure to alcohol so that they can best accommodate the learning needs of students with FASD. Yukon educators, who are knowledgeable of FASD, can help support children and caregivers affected by this disability, advocate for diagnosis, and promote prevention strategies. This study highlights current research in the area of FASD with the goal of providing an overview of the effects of prenatal exposure to alcohol and suggesting effective teaching strategies to help students with FASD develop to their full potential.

Definitions

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used by diagnosticians, researchers, and educators to describe the continuum of effects caused by prenatal exposure to alcohol (Premji, Benzies, Serrett, & Hayden, 2006). FASD is not a clinical diagnosis (Chudley, et al., 2005), rather diagnosticians use the following terms to express the range of effects caused by prenatal alcohol exposure: Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Partial Fetal Alcohol Syndrome (pFAS),
Alcohol-Related Neurological Disorder (ARND), and Alcohol-Related Birth Defects (ARBD).

**Fetal Alcohol Syndrome (FAS)** is a medical diagnosis involving confirmed prenatal exposure to alcohol, growth deficiency, characteristic facial features, and brain damage (Astley & Clarren, 2000).

**Fetal Alcohol Effects (FAE)**, although never intended to be a diagnostic term, has been used in literature to describe children who have confirmed prenatal exposure to alcohol with only partial expression of the defining FAS features (Alberta Learning, 2004). This term in no longer commonly used and has generally been replaced with Alcohol-Related Neurological Disorder (ARND),

**Partial Fetal Alcohol Syndrome (pFAS)** indicates confirmed prenatal exposure to alcohol. A student with pFAS is identified with some, but not all, of the physical signs of FAS, and demonstrates learning and behavioural challenges associated with central nervous system dysfunction (Alberta Learning, 2004).

**Alcohol-Related Neurological Disorder (ARND)** is the designation given to a student with confirmed prenatal exposure to alcohol that demonstrates a damaged central nervous system through learning difficulties, poor impulse control, deficits in memory and attention, poor social skills, and poor judgment (Alberta Learning, 2004).

**Alcohol-Related Birth Defects (ARBD)** refers to specific physical abnormalities resulting from confirmed prenatal alcohol exposure. These abnormalities may include heart, skeletal, vision, hearing, and fine/gross motor problems (Alberta Learning, 2004).

**Identification** refers to the screening, referral, and diagnosis of individuals who have been affected by prenatal exposure to alcohol.
**Intervention** is the term used to describe activities intended to lessen the severity of the primary or secondary disabilities associated with FASD. Intervention strategies may include support for high-risk mothers, early diagnosis, family support, or school-based accommodations.

**Limitations and Delimitations**

There is limited research and scientific data on the effectiveness of educational interventions specifically designed for students with FASD (Premji, et al., 2006; Roberts & Nanson, 2000). The intervention strategies described in this paper are based upon the consensus opinion of experts in the field of FASD.
What is Fetal Alcohol Spectrum Disorder?

The World Health Organization (1999) recognizes Fetal Alcohol Spectrum Disorder as the leading cause of environmentally related mental retardation and birth defects in the western world (as cited in Kyskan & Moore, 2005). Fetal Alcohol Spectrum Disorder is the umbrella term given to a range of effects caused by the mother’s consumption of alcohol during pregnancy. FASD is the result of prenatal exposure to alcohol and the fetus remains vulnerable for the entire duration of the pregnancy. The part of the fetus which is affected, and the severity, depends on when during the pregnancy alcohol was consumed, how much alcohol was consumed, and the mother’s overall genetic make-up and health (Alton & Evensen, 2006; Public Health Agency of Canada, 2007).

Alcohol damages developing cells in the fetus. When brain cells are damaged by ethanol, the body attempts to compensate by sending non-thinking cells to the damaged area. These cells create a structural layer but do not allow for proper lamination, which is the process by which connections are formed in the brain (Alton & Evensen, 2006; Sant’Anna & Tosello, 2006). This improper lamination can negatively impact the brain’s capacity for abstract thought, understanding cause and effect, memory, generalization of learning, attachment, and sexual behaviour (Alton & Evensen, 2006).

Primary Disabilities

The brain damage is permanent and the effects that the child is born with are the direct result of prenatal alcohol exposure. They are referred to as the primary disabilities (Public Health Agency of Canada, 2007). These primary disabilities can be divided into...
two categories: deficits that are the result of damage to the brain, and physical abnormalities that result from damage to other parts of the developing fetus (Alton & Evensen, 2006).

Brain function deficits may include neurological impairment, memory and attention deficits, information processing impairment, delayed or dysfunctional language skills, difficulty with verbal learning and encoding, difficulty communicating feelings appropriately, difficulty understanding cause and effect, attachment disorders, and general learning disabilities (Alton & Evensen, 2006; Public Health Agency of Canada, 2007; Clarren, 2008; Green, 2007).

Physical abnormalities may include eye and ear malformations, mouth and jaw deformation, skeletal defects, organ pathology, sensory deficits, and impaired immune system (Saskatchewan Learning, 1996).

Secondary Disabilities

The term “secondary disabilities” refers to disabilities that are not present at birth but occur as a result of the primary disability. Secondary disabilities may develop as the result of increased societal expectations of an individual as they grow older (Public Health Agency of Canada, 2007). These disabilities may include a disrupted school experience, alcohol and drug abuse, irresponsible parenting, joblessness, homelessness, mental health issues, victimization, trouble with law, and premature death (Streissguth, 1997). The outcomes of secondary disabilities could presumably be improved upon with better societal understanding and early intervention (Streissguth, Barr, Kogan, & Bookstein, 1997).
Streissguth, Barr, Kogan, and Bookstein (1997) conducted life history interviews that evaluated individuals with FASD, regardless of age or degree of disability. The results of this study are summarized below:

- 90% of patients had seen a counselor or therapist for mental health issues
- 60% of patients (12 or older) had been suspended or expelled from school, or had dropped out
- 60% of patients had experienced a run in with the law, been charged, or convicted of a crime
- 50% of patients had been confined to an alcohol/drug treatment facility or incarcerated for a crime
- 50% of patients reported repeated problems with inappropriate sexual behaviours
- 30% of patients (12 or older) had alcohol and/or drug problems
- 80% of patients (over 21) were in a dependent living situation
- 80% of patients (over 21) reported problems with employment

A study in Germany on 158 individuals with FAS found that 63% suffered from at least one persistent mental health issue, including emotional, sleep, and attention deficit and hyperactivity disorders (Steinhausen et al., 1993, as cited in Roberts & Nanson, 2000).

Another German study, which longitudinally tracked forty-four adolescents, found that up to 50% of these adolescents had emotional problems and 19% had behaviour problems (Spohr, Willms, & Steinhausen, 1994).

In British Columbia, researchers at a youth correctional facility identified that sixty-seven (or 23.3%) of the 287 remanded youth were diagnosed with FASD (Fast, Conry, & Loock, 1999). Since this prevalence rate of FASD among incarcerated youth is much higher than accepted prevalence rates in general society, it suggests that they are
disproportionately represented in the youth justice system (Fast, Conry, & Loock, 1999).

FASD and the justice system will be discussed in greater detail later in this chapter.

Streissguth (1997) suggests that there are eight “universal protective factors” that
discourage the onset of secondary disabilities (p. 35):

1. Living in a stable and nurturing home for over 72% of life
2. Being diagnosed before the age of 6
3. Never having experienced violence against them
4. Staying in each living situation for an average of more than 2.8 years
5. Experiencing a good quality home from age 8-12
6. Being found eligible for governmental support services
7. Being diagnosed as FAS (rather than ARND or ARBD)
8. Having basic needs met for at least 13% of life

These factors are found to significantly reduce the chance of mental health problems,
disrupted school, and trouble with the law (Streissguth, 1997).

**Risk Factors**

A study in the UK found that 27% of women between the ages of sixteen and
twenty-four engage in binge drinking at least once a week (Jones, Chambers, Hill, Hull,
& Riley, 2006). Binge drinking, defined as five or more drinks consumed on one
occasion, is known to cause damage to fetal development (Ebrahim, Diekman, Floyd, &
Decoufle, 1999, as cited in Malbin, 2004). Studies indicate that the majority of
pregnancies from this demographic are unplanned (Forrest, 1994). Unfortunately, this
suggests that women may continue to engage in heavy episodic drinking during the early
weeks of pregnancy, exposing the vulnerable fetus to alcohol (Jones, Chambers, Hill,
Hull, & Riley, 2006).

Parents of children born with FASD frequently have undiagnosed FASD
themselves (Malbin, 2004). In one study, thirty-five percent of mothers who gave birth
to children with FAS were themselves diagnosed with FASD (Astley, Bailey, Talbot, &
Clarren, 2000, as cited in Malbin, 2004). This same study found that 100% of these mothers whose children were born with FAS had experienced sexual, physical, or emotional abuse (Malbin, 2004).

A study by the Centers for Disease Control and Prevention in the United States, which tracked alcohol consumption of pregnant women over a seven year period, suggests that women who are higher educated, unmarried, and a smoker are at risk for drinking during pregnancy (Ebrahim et al., 1998). Employment is also a contributing factor since financial security provides the money necessary for increased access to alcohol (Ebrahim et al., 1998).

Alcohol consumption is generally associated with poor reproductive health and contributes to risky behaviour, such as unsafe sex, further placing women at risk for negative reproductive outcomes (Ebrahim et al., 1998). Testa and Reifman (1996) found that women who had drank during their first pregnancy, and experienced a healthy outcome, perceived a decreased level of risk that could lead to increased drinking during subsequent pregnancies.

**Incidence**

Researchers in the United States have reported the rate of children being born with FASD as 9.1 per 1000 births (Sampson et al., 1997). Although there are no national prevalence rates for FASD in Canada, the Public Health Agency of Canada recognizes that the above rate would result in more than 3, 000 babies born annually with FASD and approximately 300,000 individuals currently living with this disability in Canada (Public Health Agency of Canada, 2007).
Researchers from an Ontario hospital anonymously tested the meconium of 682 newborns for prenatal alcohol exposure and found that seventeen had been exposed to high levels of alcohol (Gareri, Lynn, Handley, Rao, & Koren, 2008). Meconium is the first stool of a newborn where the presence of fatty acid ethyl esters has been established as a biomarker of prenatal exposure to alcohol (Gareri et al., 2008). Overall, 3.7% of these babies had been exposed to alcohol (Public Health Agency of Canada, 2007).

Studies of smaller populations within Canada have revealed much higher rates of FASD. A prevalence rate of 190 per 1000 live births was reported in a First Nation community in northern British Columbia where 22 children were diagnosed with FAS out of 116 tested (Robinson, Conry, & Conry, 1987). A study conducted in a First Nation reserve in Manitoba estimated the prevalence rate of FASD as 55-101 per 1000 (Square, 1997). In the Yukon, the rate of FASD among First Nation children is estimated to be 46 per 1000 births (Asante & Nelms-Matzke, 1985, as cited in Chudley et al., 2005).

Further research into birth prevalence rates of FAS suggests a dramatic range from 0.26 per 1000 in middle to upper class USA, 1.7 per 1000 in an indigenous population of Australia, to 39 per 1000 in South Africa (Elliott & Bower, 2004). Rates of FASD are based upon relatively small sample sizes and should not be generalized to specific ethnocultural backgrounds (Chudley, et al., 2005).

In their study comparing per capita alcohol consumption with the prevalence rates of FAS, Kyskan and Moore (2005) found that Australia and the U.K. had lower rates of FAS “despite higher per capita rates of alcohol consumption [compared with Canada and the USA]. This counter-intuitive finding reflects under-recognition, diagnostic
difficulties due to lack of trained doctors, and the fact that FAS is not reliably reported to birth defects registries” (p. 161).

**Diagnosis**

The diagnosis of Fetal Alcohol Spectrum Disorder is complicated due to the complexity and range of dysfunction associated to prenatal alcohol exposure. Astley and Clarren (2000) state that there is likely to be full agreement on the diagnosis of FAS only when anomalies to growth, face, and brain development are all extreme and when there is substantial and conclusive evidence of prenatal alcohol exposure. However, individuals may demonstrate the cognitive, emotional, social, and behavioural patterns associated with prenatal exposure to alcohol (Green, 2007). Misdiagnosis may lead to inappropriate patient care, missed opportunities for early intervention, and increased risk for secondary disabilities (Streissguth & Kanter, 1997). Diagnostic misclassification may also lead to inaccurate estimates of persons affected by FASD, which may impede governmental efforts to allocate adequate social, educational, and health services to this vulnerable population (Astley & Clarren, 2000).

Furthermore, individuals who are diagnosed with alcohol-related neurological disorder (ARND), and not FAS, may not receive the support they require because of their lack of characteristic physical features (Chartrand, L., Forbes-Chilibeck, E., 2003).

Lemoine (1968) first documented developmental disabilities and birth defects in infants born to alcoholic parents (Chudley et al., 2005). Several years later, Jones and Smith (1973) identified a specific pattern of abnormalities, which they referred to as Fetal Alcohol Syndrome (Mattson & Riley, 1997):

- Smooth philtrum (which is the space between the nose and upper lip)
- Thin vermillion border (the red part of the upper lip)
• Impaired prenatal and/or postnatal growth
• Central nervous system and/or neurobehavioural disorders.

In response to the acknowledgement that the timing and degree of exposure to prenatal alcohol are important variables affecting the range of disabilities, the term Fetal Alcohol Effects (FAE) was created for “suspected alcohol effects” (Chudley et al., 2005). The United States Institute of Medicine continued to delineate these “effects” by creating the categories of FAS, partial FAS, alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND) (Chudley et al., 2005). These subcategories began to acknowledge the present understanding of FAS as a spectrum disorder.

Astley and Clarren (2000) developed the diagnostic strategy that is currently used in Canada (Chudley et al., 2005). There are four key diagnostic features of Fetal Alcohol Syndrome that are evaluated independently of one another using a four point scale based on the magnitude of expression (Astley & Clarren, 2000). The criterion for the 4-Digit Diagnostic Code is found in Table 1 below.

In Canada, Fetal Alcohol Spectrum Disorder remains the general term describing the range of effects caused by prenatal exposure to alcohol but is not a diagnosis. Possible diagnoses for individuals within the spectrum include: Fetal Alcohol Syndrome (FAS); Partial FAS (pFAS); Alcohol-Related Neurodevelopmental Disorder (ARND); and Alcohol-Related Birth Defects (ARBD) (Public Health Agency of Canada, 2007).

Diagnosing a Fetal Alcohol Spectrum Disorder requires a multidisciplinary diagnostic team consisting of a case management coordinator, a physician who is specifically trained in diagnosing FASD, a psychologist, an occupational therapist, and a speech-language pathologist (Chudley, et al., 2005).
Table 1

<table>
<thead>
<tr>
<th>Rank</th>
<th>Growth deficiency</th>
<th>FAS facial Phenotype</th>
<th>CNS damage or dysfunction</th>
<th>Gestational exposure to Alcohol</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Significant</td>
<td>Severe</td>
<td>Definite</td>
<td>High Risk</td>
</tr>
<tr>
<td></td>
<td>Height and weight Below 3rd percentile</td>
<td>All 3 features: PFL 2 or more SDs Below mean Thin lip: rank 4 or 5 Smooth philtrum: rank 4 or 5</td>
<td>Structural or neurological evidence</td>
<td>Confirmed exposure to high levels</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Probable</td>
<td>Some Risk</td>
</tr>
<tr>
<td></td>
<td>Height and weight below 10th percentile</td>
<td>Generally 2 of the 3 features</td>
<td>Significant dysfunction across 3 or more domains</td>
<td>Confirmed exposure. Level of exposure unknown or less than rank 4</td>
</tr>
<tr>
<td>2</td>
<td>Mild</td>
<td>Mild</td>
<td>Possible</td>
<td>Unknown</td>
</tr>
<tr>
<td></td>
<td>Height or weight below 10th percentile</td>
<td>Generally 1 of the 3 features</td>
<td>Evidence of dysfunction, but less than rank 3</td>
<td>Exposure not confirmed present or absent</td>
</tr>
<tr>
<td>1</td>
<td>None</td>
<td>Absent</td>
<td>Unlikely</td>
<td>No Risk</td>
</tr>
<tr>
<td></td>
<td>Height and weight at or above 10th percentile</td>
<td>None of the 3 features</td>
<td>No structural, neurological or functional evidence of impairment</td>
<td>Confirmed absence of exposure from conception to birth</td>
</tr>
</tbody>
</table>

PFL = palpebral fissure length; SD = standard deviation

With the 2005 publication of *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis*, Canada began to standardize the diagnostic procedures for FASD using the 4-Digit Diagnostic Code criteria for FASD (Public Health Agency of Canada, 2007). However, many individuals with FASD remain undiagnosed because of the need for more diagnostic teams (Public Health Agency of Canada, 2007). There are currently two clinical programs in the Yukon diagnosing using the Canadian Guidelines (Clarren, 2008). Special Programs, at the Yukon Department of Education, is responsible for the diagnosis of school-age children and the Fetal Alcohol Syndrome Society of
Yukon (FASSY) provides diagnostic clinics for adults (Alton & Evensen, 2006). The Yukon Medical Officer estimates that twenty-four children are born with FASD in the territory each year (Alton & Evensen, 2006) while the number who were formally identified with FASD between January 2005 and May 2006 was twenty-one (Clarren, 2008). The clinics are relatively new to the territory and the backlog of undiagnosed clients accounts for the relative closeness between estimated annual cases and the number being diagnosed.

There continues to be the need for fully validated common screening and diagnostic tools that are adapted for the numerous ethnic groups that comprise the Canadian population (Public Health Agency of Canada, 2007). For example, the length of the palpebral fissure (eye slit) has been considered a key indicator of FASD despite clinicians being uncertain if there are important racial differences in length caused by the epicanthal folds (Clarren, 2008). Chosen for the vast ethnic diversity, researchers are currently compiling data collected at Vancouver schools of over 2000 measurements of epicanthal folds (Clarren, 2008).

**The Importance of Early Diagnosis**

Researchers agree that early identification and intervention, designed with a greater understanding of the unique needs of FASD, will result in an improved quality of life for individuals with FASD and their caregivers (Streissguth, 1996; Green, 2007; Sant’Anna & Tosello, 2006). In one study, it was recognized that a diagnosis before the age of six significantly reduced the occurrence of secondary disabilities except for issues with mental health (Streissguth, 1996).
Early diagnosis of FASD will initiate the allocation of appropriate intervention and resources that will help mitigate the development of secondary disabilities (Chudley et al., 2005).

Early identification also provides the opportunity for aggressive intervention with the mothers, in the form of counselling and treatment, hopefully preventing the recurring pattern of drinking while pregnant and the future birth of affected children (Burd, 2006; Chudley et al., 2005). Furthermore, diagnosis of the child during infancy allows for the identification of mothers who are high risk because of alcohol abuse, allowing for support and advocacy to be provided to mitigate their alcoholism, and provide counselling for family planning (Streissguth, 1998).

**Intervention Strategies – Life Span Approach**

*During Infancy (birth – 5 years old)*

Streissguth (1998) states that the primary focus during infancy should be identification of FASD and ensuring that the child is in a physically safe environment with caregivers that are knowledgeable and capable of caring for the special needs of the child. Tremulousness, irritability, disrupted sleep/wake cycles, weak suckle, and failure to thrive are conditions of FASD that may suggest compromised central nervous system (Streissguth, 1998). Identifying these conditions may prompt caregiving activities that will be mutually beneficial to both the child and the caregiver (Streissguth, 1998).

Habituation, which is a basic function of the central nervous system during infancy, protects the infant from having to respond to excessive stimulation in the new environment that is not related to immediate survival (Streissguth, 1998). Researchers have identified poor habituation as one of the earliest and strongest indicators of prenatal...
exposure of alcohol to the central nervous system (Streissguth, Bookstein, Sampson, & Barr, 1993, as cited in Streissguth, 1998). Identifying this condition will allow caregivers to shelter the child from excessive stimulation and can program stimulating activity around the child’s sleep/wake cycle (Streissguth, 1998).

O’Connor (2001) suggests that prenatal exposure to alcohol is a significant risk factor in the development of depressive features later in life because of the direct effect of in utero exposure to alcohol and the indirect effect of infant negative affect. Early intervention programs that target problematic behaviours in infants, designed to be developmentally appropriate, may have positive outcomes for early mood disorders (O’Connor, 2001).

Researchers and clinicians agree that “given the brain’s plasticity in infancy and early childhood, beginning interventions early may maximize the personal potential of children with FASD by assisting them in adapting to cognitive, behavioural and functional difficulties, and reducing secondary disabilities” (Premji et al., 2006, p. 390).

LaDue (1989) recommends that a case manager be assigned to coordinate services, such as the enrolment in an appropriate preschool, supporting parents by educating them around the needs of a child with FASD, and providing caregivers with respite care (as cited in Streissguth, 1998). The case manager of the preschool support services should ensure that the school district is informed, ideally a year prior to the commencement of the child with FASD at school, so that special services, including an Individual Education Plan, are established to facilitate a smooth transition (Manitoba Education, 2001).
Recognizing the importance of early diagnosis as a precursor to appropriate intervention, Burd (2006) recommends more intensive, systematic screening at publicly funded child development programs that serve high-risk populations.

*Latency (6-11 years old)*

Streissguth (1998) recommends that parents or caregivers, when enrolling their child with FASD into school, ensure that the teacher is knowledgeable of FASD and will use short, clear instructions, teach both verbally and visually, and create an environment where the child will succeed. Studies show that the slower cognitive pace of many children with FASD, as the result of their brains taking longer to process information, may result in students with FASD understanding only every third word in verbal-only instruction (Alton & Evensen, 2006).

Negative experiences, such as repeated failure, peer pressure, inability to understand tasks, and having insufficient time to complete task, may lead to loss of control within the child, resulting in behavioural challenges (Streissguth, 1998). For an effective behaviour intervention to be planned and implemented, educators must not view

“the behaviour problems as a result of the child being ‘defiant,’ ‘lazy,’ ‘intentional,’ or ‘manipulative.’ These behaviours should be viewed as symptoms of underlying neurocognitive deficits in [executive functioning]” (Green, 2007, p. 106).

Furthermore, the development of children with FAS has been observed as inconsistent, seemingly normal at times and delayed at other times (Weiner & Morse, 1994).

If the child with FASD does not exhibit significant hyperactivity, the first three years of school may pass without significant challenge, and some children with FASD may actually demonstrate above average skills in decoding (Streissguth, 1998). However,
third grade usually becomes difficult for these students because of greater demands in abstract thinking and number processing (Streissguth, 1998).

The following are the concerns and problems associated with the latency period (LaDue, n.d.). Alcohol-affected students may:

- be easily influenced by others
- have difficulty predicting and/or understanding consequences
- present the appearance of capability without actual abilities
- have difficulty separating fact from fiction
- demonstrate temper tantrums, lying, stealing, disobedience and defiance of authority
- have delayed physical and cognitive development
- possess poor comprehension of social rules and expectations

A safe, structured home environment, appropriate educational placement, the use of clear, concrete, immediate consequences to inappropriate behaviour, and the structuring of leisure time are recommended interventions for this age category (LaDue, n.d.).

Parents and caregivers may require support in fully acknowledging their child’s special needs and may need support in developing realistic goals and expectations (LaDue, n.d.).

*Adolescence (12 – 17 years old)*

As a child with FASD becomes an adolescent, “families are faced with the jarring recognition that their child is not fitting the expected pattern of development and is not catching up” (Streissguth, 1998, p. 136). The difficulties associated with this age can be tremendous. They are summarized below and will guide the discussion of this important developmental phase (LaDue, n.d.):

- Faulty logic
- Difficulty comprehending and/or responding appropriately to other people's feelings, needs, and desires
- Low motivation
- Low self-esteem
• Academic ceiling is lower than an IQ test may suggest, especially in mathematics
• Depression and suicidal thoughts
• Alcohol and drug abuse
• Inappropriate sexual behaviour
• Pregnancy or fathering a child
• Loss of place to live/residency
• Lying, stealing, vandalism, involvement of the law

Individuals with FASD, as they enter adolescence, are faced with the reality of greater societal expectations on behaviour. In the case of stealing, Kleinfeld, Morse, and Wescott (2000) reminds us that “[w]hen a child takes what he wants at four years of age, it is annoying; When a young person takes what he wants at 14 years of age, it is stealing” (p. 329). Unfortunately, “standard disciplinary techniques are not usually effective for people with FASD [since] these traditional methods of punishment presume a normally functioning brain that readily understands the concept of negative consequences for inappropriate behaviours” (Malbin, 2004, p. 56). A study by Fast et al. (1999) found that the types of crimes most often committed by adolescents with FASD were theft (43%), assault (39%), failure to comply/breach of parole (43%), and mischief/vandalism (21%).

It is not uncommon for individuals with FASD to become involved with inappropriate sexual situations that may leave them vulnerable to victimization, reduced self esteem due to rejection, or, in extreme cases, prosecution (Streissguth, 1998). Caregivers must prepare for this eventuality by developing habits with their child before adolescence. For example, Kleinfeld, Morse, and Wescott (2000) reported that one father made sure that he never relieved himself while hiking with this son in the woods because his son may not understand that while it is acceptable to do so in the woods because his son may not understand that while it is acceptable to do so in the woods, it is inappropriate to do so in the city streets. Although it may be acceptable to take off one’s clothes in public as a
small child, it can become a serious problem if done by a teenager (Kleinfeld, Morse, & Wescott, 2000). Caregivers must carefully plan for adolescence, anticipating potential areas of difficulty, and begin to develop positive habits in their child at a very early age.

Sexual behaviour must be taught explicitly to children with FASD. For example, Miranda and Levine (2000) suggest that the rule caregivers tell adolescents about masturbation is that it “should be only done in private in [the] child’s bedroom,” instead of creating the potential for inappropriate behaviour resulting from a misinterpretation of what “private” means (p. 213).

Sexual education, rules surrounding sexual behaviour, and the use of birth control, must be explicitly taught to individuals with FASD by their families (Streissguth, 1998). Rules surrounding sexual behaviour that may endanger the individual, or have legal consequences, must be concrete, rigid, and absolute (Miranda & Levine, 2000). The rule format of “Always do this – Never do that,” simplifies the decision making process because “[c]hildren with FAS do best with a highly consistent routine because such structure reduces demands on the brain to process new information” (Morse, 1993, as cited in Miranda & Levine, 2000, p. 212). The consequence of insufficient education in the area of sexual behaviour and birth control is clearly evident in a study of thirty women with FASD who had children: 54% did not care for all of their children, 36% of these children were removed by children’s protective services, and 40% of these women reported drinking during at least one pregnancy (Grant, Ernst, Streissguth, & Porter, 1997, as cited in Streissguth, 1998).

Depression and suicide ideation can begin to develop during adolescence. Evidence from preliminary studies indicate “that early-onset damage to prefrontal brain structures
from FAS/FAE may have devastating consequences on the emergence of adaptive behaviour throughout development [resulting in] disorders of personality, social behaviour, and executive functions such as planning and decision-making” (Tranel & Eslinger, 2000, as cited in MacNeil, 2008, p. 9). The damage to the prefrontal brain that leads to the abovementioned disorders may significantly contribute to the decisions that lead to suicide (MacNeil, 2008).

Baxter (2000) describes a case study of an adolescent woman who expressed an understanding of death as “an end to discomfort, but not as an end of living” (p. 173, as cited in Kleinfeld, 2000, p. 173). This woman made threats and gestures of suicide when she became overwhelmingly frustrated with her lack of understanding. Her behaviour and threats were an expression of her feeling of total helplessness (Baxter, 2000, as cited in Kleinfeld, 2000).

The Canadian Paediatric Society (2002) suggests, “Aboriginal youth affected by FAS may manifest poor judgment, an inability to appreciate consequences of actions, and difficulty in sequencing actions” (MacNeil, 2008, p. 9). FASD may explain why First Nation suicide rates for completed versus attempted are higher, why suicides appear unplanned and more spontaneous, and why they may lack traditional risk markers such as premeditation (MacNeil, 2008).

Streissguth (1997) reported that completion of high school by individuals with FASD was difficult and that many experienced a disrupted high school experience which included suspensions, expulsions, and dropping out. This negative outcome, or secondary disability, is almost certainly a consequence of their vulnerability to various risk factors associated with FASD (Duquette, Stodel, Fullarton, & Hagglund, 2006, p. 228).
Research suggests that the primary protective factor that may mitigate these hazards is a supportive family who actively advocates for a formal diagnosis, ensures proper accommodations at school, and provides emotional and academic support at home (Duquette et al. 2006).

Murray (2003) identified several protective factors related to family which may prevent dropping out of school: secure relationship between the child and the caregiver, warm but demanding parenting style, family composition, caregiver level of education, caregiver employment, and high expectations for the child (as cited in Duquette et al., 2006). These factors, coupled with resiliency on the part of the individual who succeeds in spite of risk and vulnerability, can create a positive outcome in regards to high school completion (Duquette et al., 2006).

Adolescents with FASD, like most teenagers, will begin to seek more freedom and independence in their lives. Streissguth (1998) states, “premature relinquishment of parental control only opens the door for less responsible authorities to assume leadership,” such as peer-groups (p. 136). Families that are able to provide an appropriate amount of autonomy and responsibility while maintaining a supportive and stable environment will have a greater chance of monitoring and guiding the behaviour of the adolescent with FASD (Streissguth, 1998).

Adulthood (18+ years old)

Many of the difficulties encountered during childhood and adolescence will remain into adulthood. Individuals with FASD are best prepared for adulthood if they prolong their adolescent-type relationship with their families as long as possible.
(Streissguth, 1998). The needs of the adult with FASD are summarized below (LaDue, n.d.):

- Poor comprehension of social expectations
- Require economic support and protection
- Job training, mentorship, and placement
- Depression and suicide ideation and attempts
- Social, sexual, or financial exploitation
- Withdrawal and social isolation
- Unpredictable and impulsive behaviour

LaDue (1989) recommends that an adult with FASD will require substantial support and advocacy in the form of guardianship over finances, case manager support to oversee residential placements, specialized vocational training and job placements, and in-home support services for those who are able to live independently (as cited in Streissguth, 1998).

Acknowledging that FASD is a lifelong disability, continued support of adults with FASD is essential. A study from British Columbia assessing the secondary disabilities of adults with FASD found that 92% were considered “vulnerable to manipulation,” in the form of false confessions to authorities, acquiescence, and difficulty understanding consent (Clarke, Minnes, Lutke, & Ouellette-Kuntz, 2007). The findings of this study emphasized the dichotomy between IQ and the need for support. Thirty-four percent of the clients had an IQ less than 70 (or below average), yet 81% of the individuals in the study required moderate to high levels of support suggesting poor adaptive behaviour (Clarke, Minnes, Lutke, & Ouellette-Kuntz, 2007).

Mental health issues are common among adults with FASD. Data collected during a pilot community intervention project found that 70.6% of women involved with the study had received a psychiatric evaluation (Grant et al., 2004). Clarke, Lutke, Minnes, and
Ouellette-Kuntz (2004) found an extremely high percentage of 92% of their clients had a mental health diagnosis. This high co-morbidity rate may reflect the lack of support for individuals with FASD, which may contribute to mental health issues such as depression (Phillips & Johnson, 2001, as cited in Clarke, Lutke, Minnes, & Ouellette-Kuntz, 2004).

**Fetal Alcohol Spectrum Disorder and the Justice System**

According to data collected by Streissguth, Barr, Kogan, and Bookstein (1997), more than sixty percent of individuals with FASD over the age of twelve have experienced encounters with police. The apparent collision between individuals with FASD and the justice system occurs all through the lifespan and is therefore discussed outside of the age framework.

The characteristic effects of FASD can amount to what Byrne (2002) calls “a recipe for disaster” in regards to coming into contact with the law and for re-offending (p. 2). These characteristics, although mentioned previously in this paper, are worth repeating in the context of the FASD experience in the justice system. The characteristics may include: impulsivity, poor judgment, lack of understanding of cause and effect, difficulty predicting and/or understanding consequences of behaviour, inability to learn and generalize from past mistakes, and poor social skills. Also, individuals with FASD have “better expressive language skills than receptive language skills so they appear to understand more than they actually do” (Byrne, 2002, p. 2). Williams (2006) states that since “justice systems basically are designed to punish social irresponsibility, it is not surprising that many individuals with an FASD ultimately enter the juvenile justice system” (p. 8).
When an individual with FASD is placed under arrest there are immediate challenges caused by their information processing deficits and cognitive ability. The account of any incident by an individual with FASD, the understanding of matters like Miranda warnings [right to remain silent], illegal search and seizure, and the right to representation is, at best, questionable (Williams, 2006). Worst-case scenarios involve individuals who confess to a crime they did not commit just to end the discomfort of being questioned by the police (Williams, 2006).

Police will often be unaware of the inability of the individual with FASD to comprehend the seriousness of the situation or to make decisions in regards to representation (Williams, 2006).

Conry and Fast (2000) comment on the vulnerability of both accused and victim during legal proceedings when they have FASD (as cited in Moore & Greene, 2004):

“an accused person with [FASD] may give false confession or a false statement and, in court, may appear confused or give contradictory explanations. A witness . . . may interpret questions too literally or deny something that seems obviously true. The victim with [FASD] may not clearly remember details of time, place, and sequence, and may be easily influenced by leading questions.”

The question becomes whether or not the individual with FASD is fit to stand trial. Dagher-Margosian (1997) argues that the defendant may be incompetent to stand trial if he/she is unable to understand the proceedings or unable to assist the defense attorney during the court proceedings. Unfortunately, Byrne (2002) suggests “many persons without the full physical signs of FAS, but with the neurodevelopmental disability, who come into conflict with the law, are not recognized as disabled and are not assessed to find out their level of ability” (p. 2).
Moore and Greene (2004) emphasize that individuals with FASD challenge the underlying principle that defendants understand the relationship between their actions, outcomes, intentions, and punishment. The Yukon Territorial Court describes similarly the difficulty sentencing offenders with FASD:

“Lacking sufficient cognizance of the threat or fear of consequences, the FAS patient is less likely to control his or her impulsive behaviour. Similarly, FAS individuals have trouble comprehending that their behaviour affects others. As such, they are unlikely to show true remorse or to take responsibility for their actions” (Moore & Greene, 2004, p. 3).

Williams (2006) describes why sentencing that is based upon the principles of general deterrence are not achieved beyond the period of detention: “the juvenile’s actions were not taken with the intent to commit a crime, the underlying cause of the dysfunctional behaviour has not been addressed, and treatment has not been provided” (p. 9). Contrary to the goals of incarceration, convicted individuals with FASD are often physically and sexually abused by other inmates, set on the path of future criminality by learning more about criminal acts, and will not have made the connection as to what they did to end up incarcerated in the first place (Williams, 2006; Byrne, 2002).

Williams (2006) suggests that the following systematic changes be made to better serve justice in regards to individuals with FASD: increase FASD training among members of the justice system, increase the number of individuals referred for diagnosis, recognize FASD as a mitigating, or sometimes exculpatory, factor, and develop alternative sentencing options. Malbin (2004) believes that “the courts are in an important position to increase awareness of this problem and support development of effective strategies to prevent reoffending simply by asking whether FASD is a factor that needs to be considered” (p. 62).
Boland et al. (1998) recommend a screening instrument for identifying inmates with FASD be developed for use in Canadian federal prisons, and improved access to diagnostic services with the correctional system (Roberts & Nanson, 2001). This identification, coupled with increased FASD training for correctional staff, could lead to more appropriate services such as simplified versions of anger management, life skills and substance abuse programs (Roberts & Nanson, 2001). Chartrand & Forbes-Chilibeck (2003) recommend that provinces and territories explore the establishment of mental health courts or, where the population base cannot support such a court, then mental health counselors/commissioners be assigned who would coordinate services for individuals with FASD.

Young offenders with FASD reportedly do well in the highly routine environment of a correctional facility, often receiving early release for good behaviour (Roberts & Nanson, 2001). Unfortunately, they do not have the skills required to transition to an unstructured environment resulting in a high recidivism rate (Conry & Fast, 2000, as cited in Roberts & Nanson, 2001). The following chapter provides education-based intervention strategies that will hopefully lessen the likelihood of adolescents becoming involved with the justice system.
Chapter Three
Educational Strategies for Individuals with FASD

Teachers who have the knowledge and understanding of FASD can be a positive influence in the lives of students who are living with the disability. The school is often the most important institution in the community to effectively intervene in the lives of children with FASD and their families (Streissguth, 1997). The following chapter highlights practical strategies for teaching students with FASD.

Environmental Strategies for the Classroom

Students with FASD may react differently to their physical environment than their peers because of the way in which they process their surroundings. Sensory integration is the ability to receive, sort, and process information received from our bodies and environment, and then interpret, organize and respond accordingly (Alton & Evensen, 2006). Students with sensory processing difficulties may appear (Croskery, 2005):

- unsure of their body position
- poor at planning body movement
- poorly coordinated
- easily distracted by what they see, hear, or feel and consequently have limited attending skills
- highly active or under-aroused

Sensory hypersensitivity, caused by the inability of the brain to sort incoming stimuli effectively and consistently, may “contribute to problems with eating, sleeping, activity levels, learning, and behaviour” (Weiner & Morse, 1994, p. 68). The bright lights, stimulating bulletin boards and displays, and the loud noise associated with simultaneous activities of the typical elementary classroom may overwhelm students with FASD (Alberta Learning, 2004). Sensory stimulation, such as sound, touch, and light, needs to be limited in the classroom since overstimulation may “severely and negatively
impact their learning” (Murphy, 1993, as cited in Weiner & Morse, 1994, p. 70). The ideal learning environment matches the level of stimuli with the child’s ability to make sense of stimuli from their environment (Alberta Learning, 2004).

Visual Strategies

Tanner-Halverson (1997) recommends limiting the number of objects and displays, such as bulletin boards, and further reducing the visual stimulation by covering up visual displays with a blue-gray cloth when they are not being used for instruction.

The physical layout of the classroom, the arrangement of furniture and the use of partitions, should discourage running and provide a low-traffic area where the child with FASD can work independently (Alberta Learning, 2004; Manitoba Education, 2001). Students with FASD should be provided with preferential seating where they can clearly see the teacher speak so that they are receiving both auditory and visual input during lessons (Tanner-Halverson, 1997). Study carrels may be useful in breaking up the space in the classroom and may reduce visual distractions caused by the environment and other students (Alberta Learning, 2004; Saskatchewan Learning, 2004). Tanner-Halverson (1997) reminds that the carrel, which she refers to as “the office,” should be used as a privilege and never as a punishment (p. 81). The student’s desk should remain uncluttered (Alberta Learning, 2004; Saskatchewan Learning, 2004). Students with FASD may benefit from having a designated place in the classroom, or school, that they can go to for a quiet time (Manitoba Education, 2001; Saskatchewan Learning, 2004).

Students with FASD benefit when space is made visually concrete with floor mats, rugs, hula-hoops or masking tape that clearly delineate their space (Region 6 FASD Sub-Committee, 2003).
The lighting in a classroom may be distracting to a child who has difficulty with sensory integration. Artificial lighting may be stressful and may need to be reduced by possibly reducing the wattage of the bulbs or leaving some lights off (Alton & Evensen, 2006). Full-spectrum lighting and natural lighting are generally better than fluorescent lights (Region 6 FASD Sub-Committee, 2003). Window coverings may also be considered to reduce the effects of light and the distraction of activity outside of the school (Alberta Learning, 2004). If the sensitivity to light is extreme, dark sunglasses worn inside may lessen the glare and visual distractions (Region 6 FASD Sub-Committee, 2003).

Auditory Strategies

It is important to evaluate the classroom for sounds that may disturb a child with FASD who experiences auditory sensory integration difficulties. Sounds that most people consider ambient, such as the sounds of a fan, heating systems, air conditioners, or humming lights, may be very distracting to a child with FASD (Croskery, 2005). Efforts should be made to minimize these background noises. Steps should be taken to mitigate hallway traffic passing by the classroom, as well as noises from adjacent classrooms (Alberta Learning, 2004).

A plain or neutral-coloured carpet should be used in the classroom to reduce the noise level and echoing (Alton & Evensen, 2006; Alberta Learning, 2004). Acoustic ceiling tiles that will limit the amount of reflected sound should be used to further reduce echoing (Alberta Learning, 2004). Tennis balls, or carpet, placed on the legs of chairs and desks will further quiet the classroom (Alberta Learning, 2004).
The use of a sound field system, which is a surround-sound voice amplification system, may assist the child with FASD process verbal information (Saskatchewan Learning, 2004).

Headphones may be provided to the student with FASD to block out distracting noises such as a ticking clock, or the teacher talking to another student (Kleinfeld & Wescott, 1993). Headphones may also be used to listen to relaxing music that promotes a calm atmosphere (Saskatchewan Learning, 2004).

**Strategies for Reinforcing Routine and Developing Organization Skills**

Having a classroom with well-defined areas, and pictorial cues of class routines, may decrease the disorganization of a child with FASD, increase the child’s sense of control, assist in memory, and satisfy the child’s need for structure (Tanner-Halverson, 1997). Displaying detailed visual schedules and a visual representation of concrete rules, placed in close proximity to the child with FASD, will encourage understanding and compliance (Green, 2007). Student’s copies of their schedules should be posted in their lockers, binders, and/or desks, according to age and ability (Alberta Learning, 2004).

Visual supports, such as Boardmaker pictures, can be used as a general classroom schedule, to structure certain parts of the school day, such as lunch time or recess, or to structure a specific activity, such as going to the bathroom or completing a particular assignment (Alton & Evensen, 2006). Specific checklists, with visual supports, can be strategically placed around the classroom at places such as the coatroom, the listening centre, and the reading centre to reinforce the routines unique to those places (Alberta Learning, 2004).
Teachers should post a large weekly timetable on the wall, as well as a monthly calendar, and constantly refer to these schedules in order to make the day both routine and predictable for the student with FASD (Lasser, 1999). Using timetables and calendars also helps to make the concept of time more concrete, and demonstrates that there are predictable patterns to the school year (Alberta Learning, 2004).

Lasser (1999) recommends using boxes to hold school supplies, labeled with words and pictures, and/or colour-coded by subject, and always kept in the same location. This will promote independence for the student with FASD since they can borrow supplies without asking (Lasser, 1999; Alberta Learning, 2004). Students should also be encouraged to store their personal supplies, such as binders and pencil cases, in the same location when they complete an activity or finish the day (Alberta Learning, 2004).

Non-classroom settings, such as a lunchroom or the playground, may be difficult for students with FASD and require additional planning and coordination between staff. All school personnel should be aware of the specific needs of alcohol-affected students. Strategies for addressing these challenges include (Alberta Learning, 2004; Saskatchewan Learning, 2004):

- the use of a “buddy system” at recess or lunchtime
- considering alternate recess times
- considering an alternate lunch location with fewer students
- clearly posted rules and procedures
- teaching recess and lunchtime routines
- providing clear choices of activities (such as intramural sports, computer lab, clubs)
- assigned seating in lunchroom and other non-classroom settings
- consistent rules from all teachers and supervisors
Strategies for Daily Transitions

Transitions between activities, or locations, can be difficult for students with FASD who lack a good understanding of the concept of time. A predictable timetable of activities, and consistent routines, promote a student’s self-control and level of comfort in their environment (Alberta Learning, 2004). Changing activities, or moving from one place to another, can be a cause of anxiety and an opportunity for disruptive behaviour to occur (Alberta Learning, 2004). While transitioning from one activity to another, consider the following steps (Region 6 FASD Sub-Committee, 2003):

1. Forewarn: Alert students a few minutes before an activity is over.
2. Anticipate: Restate the change. Expect and plan for resistance. Wait a few minutes.
4. Act: State the immediate action

Using visual clues, such as visual schedules on a student’s desk or an egg timer, will help reduce the anxiety around transitioning because the concept of time is made more concrete (Alberta Learning, 2004).

Transitions need to be considered an activity in and of themselves, with a beginning, middle, and end (Alberta Learning, 2004). Transitions need to be incorporated into daily routines and considered part of that routine (Region 6 FASD Sub-Committee, 2003).

Strategies for the Development of Social Skills

Students with FASD who experience difficulties with social skills may act younger than their chronological age, have no friends their age, have difficulty in sports because they cannot understand the rules, have problems with time management, come to school dirty, exhibit parallel play beyond early childhood, disregard personal space, be
naïve and gullible, and disturb others by saying or doing inappropriate things (Alberta Learning, 2004). The goal of teaching social skills to students with FASD is to teach behaviours that will foster acceptance by their classmates, teachers, and other people they will encounter in their lives (Alton & Evensen, 2006). Green (2007) suggests “the use of cognitive-behavioural strategies, such as social skills training, emotion identification, coping skills, anger management, and self-talk may be helpful for children with FASD” (p. 107). Social skills are generally taught in the following sequence (Manitoba Education, 2001):

1. Identify the skill to focus on
2. Teach, review, reteach
3. Model and role-play
4. Provide feedback and reminders
5. Transfer and generalize to other locations

Additionally, Alton and Evensen (2006) add two steps specific to FASD:

6. Ensure that the student with FASD has someone to check with when she/he forgets what to do and does not understand
7. Be aware that the fact that the student with FASD can tell you the steps or rules to a specific situation does not necessarily mean they understand

Social Stories

Social stories, first developed by Carol Gray for use with individuals with Autism Spectrum Disorder, are a tool used to directly teach students with disabilities appropriate social behaviours, new social skills, and for developing routines (Manitoba Education, 2001). These stories are designed to answer who, what, where, when, and why questions about how to act appropriately in social situations (Saskatchewan Learning, 2004). Social stories will often include visuals for better understanding. These stories will be read to, or with, the student with FASD prior to a specific social situation (Saskatchewan
Social stories are most effective when they include sensory details that provide context, are descriptive, and do not include too many rules or directives (Alton & Evensen, 2006). See Appendix A for an example of a social story.

**Role-playing**

Students with FASD who have difficulty managing their behaviour in social situations may not make friends or be accepted by their peers. Role-playing is one strategy that can be used to teach the body cues related to abstract feelings, how to manage personal safety, and learn to respect personal space (Alton & Evensen, 2006). Role-playing allows individuals with FASD to learn and practice communication and social skills in a variety of settings (Alberta Learning, 2004). Role-plays can be facilitated in several ways: one-on-one with an adult, in pairs of students, small groups, or as a whole class activity (Alberta Learning, 2004).

Since many students with FASD do not generalize information from one setting to the next, it is important to teach social skills through role-plays in locations such as hallways, cafeterias, and gymnasiums (Alberta Learning, 2004). Role-playing social situations in real-life context will help make expectations more concrete to the student with FASD.

**External Brain**

Students with FASD will have difficulty recognizing similarities between social situations and, even with repetition and practice, will always require cueing from a support person (Alton & Evensen, 2006). Sterling Clarren developed the concept of the “external brain” as a means of illustrating the lifelong need of the individual with FASD to receive guidance, direction, and assistance with decision-making from an outside
source of support (Doctor, 2000). This support “may come in the form of environmental modifications, making abstract rules more concrete, teaching individuals to ask for help, and providing ongoing supervision and prompts for self-monitoring” (Green, 2007, p. 107).

The T-Chart

Using t-charts can help students with FASD understand specific rules because they are more concrete and visual (Price, 2006). A t-chart is designed for one particular rule, such as “Clean the kitchen after using it,” which is at the top of the chart. The left column is titled “looks like” and has a digital photo of the actual clean kitchen and several tasks to complete, such as “Counters are wiped and shiny,” “Floor does not have anything on it,” and “Milk is in the fridge.” The right hand column is titled “sounds like” and has a digital photo of the teacher smiling with dialogue written below: “Good job, Kobi. I really like the way you cleaned up everything on the counter, on the table and on the floor!” (Price, 2006). Although, this example was designed for a high school student who could read, the t-chart could be used at all levels of development by modifying the amount of pictures and text.

Strategies for Behaviour Management

Students with FASD will have difficulty following school and classroom rules because they are unable to understand what is expected of them (Lasser, 1999). Classroom rules must be simple, specific, and routinely followed in order for a student with FASD to understand (Lasser, 1999). Idioms and abstractions, such as “keep your hands and feet to yourself,” are confusing to students with FASD and should be made simpler and more concrete: “Don’t hit” (Lasser, 1999).
Inappropriate behaviour by a student with FASD may in fact be a misguided attempt at communicating that the task is too hard, the timeframe in order to complete the task is too short, or that the student is frustrated and does not know how to start the assigned task (Streissguth, 1997). See Appendix B for a table of commonly misinterpretations of responses by students with FASD.

Students with FASD do not benefit from traditional behaviour management techniques or traditional reward systems since they lack the memory to learn from previous mistakes and do not understand how controlling their behaviour now will benefit them in the future (Region 6 FASD Sub-Committee, 2003). Other strategies that will not work for students with FASD include (Region 6 FASD Sub-Committee, 2003):

- Taking things away
- Natural and logical consequences
- Behavioural contracts
- Loss of privileges
- Canceling or changing trips/activities because of a behaviour
- Debating, negotiating, or explaining rules or infractions

Evensen (2000) suggests replacing behaviour modification strategies, namely punishment, with an approach that includes observing the needs of the student with FASD, using role-playing to facilitate the development of new behaviour patterns, and then reinforcing these new behaviours through multisensory teaching strategies.

Behaviour in students with FASD can improve with changes to their classroom environment (Price, 2006). Changes include the physical modifications discussed previously, as well as the role of the teacher, which is to ensure that positive interactions are maximized while punitive consequences are minimized (Manitoba Education, 2001). The teacher must accept that the student with FASD has an invisible disability that prevents generalization or learning from previous mistakes, establish a
positive, caring relationship with the child, and seek the answers to the following questions when misbehaviour occurs (Lasser, 1999):

- Why is this happening?
- What has been tried?
- Why hasn’t worked?
- What has worked in the past?
- Why has it worked in the past?
- What has changed so strategies that helped previously no longer do so?

**Communication Strategies**

Students with FASD often have difficulties with language that are not immediately obvious to others because their expressive language, and their vocabulary, are often superior to their receptive language (Alberta Learning, 2004). Individuals with FASD often use abstract concepts when they speak without truly understanding what the concepts mean (Alton & Evensen, 2006).

The following suggestions should be considered when giving information to a student with FASD (Region 6 FASD Sub-Committee, 2003; Alberta Learning, 2004):

- Be sure that the student is paying attention to you before starting
- Ensure eye contact
- Exaggerate facial and body language
- Refer to people by their names rather than “them” or “they”
- Use the same words for the same instruction every time
- Make your point in 5 seconds (10 words)
- State what is to be done (“Put your feet on the floor.”)
- Avoid asking rhetorical questions
- Reduce abstract speech (Say “Put books on shelf” instead of “Tidy up room.”)

Talk alone will be insufficient for many students with FASD to understand the information being presented. Students will require visual supports, such as drawings or photographs, to help them understand (Alton & Evensen, 2006).
Strategies for Improving Memory

Students with FASD have deficits in working memory, which is an educational disadvantage that may exacerbate secondary disabilities (Loomes, Rasmussen, Pei, Manji, & Andrew, 2006). Studies indicate, however, that the deficits are in the process of encoding, rather than in information recall (Pei, Rinaldi, Rasmussen, Massey, & Massey, 2008). These findings suggest that teaching strategies, such as rehearsal training, to students with FASD can improve memory.

Teaching Memory Strategies

Students with FASD will benefit from the explicit teaching of memory strategies (Alton & Evensen, 2006). Students with FASD who were taught to repeatedly whisper the names of new objects over and over to themselves significantly improved their scores on memory tests (Loomes, et al., 2006). Students will also benefit from learning memory strategies such as organizing by category, using music and songs, and using external prompts (Alton & Evensen, 2006).

Teaching mnemonics to students with FASD may be beneficial when new facts or concepts are presented. An example of a mnemonic for remembering long division may be Doctor-Sister-Mother-Brother (Alberta Learning, 2004, p. 91):

Doctor – Divide  
Sister – Subtract  
Mother – Multiply  
Brother – Bring Down

Visual Aids to Assist Memory

Using graphic organizers, such as memory maps, will improve a student’s ability to think in terms of visual relationships and will promote the retention of information (Tanner-Halverson, 1997). Memory maps, or idea webs, aids encoding and recall
because the information is represented in multiple ways (Loomes, et al., 2006). Technology, such as Inspiration mind mapping software, may assist with recall because it is visual, repetitive, is hands-on, and represents information in multiple forms.

Lessons should include multisensory cues, such as videos, photos, colour coding, charts, or drawings, to encourage the retention of key information by students with FASD (Saskatchewan Learning, 2004; Alberta Learning, 2004). Students should be encouraged to use a highlighter to separate key information from secondary (Saskatchewan Learning, 2004).

Students with FASD should be encouraged to make lists, note dates and assignments on a calendar or in a day planner, and use checklists to ensure the completion of daily activities (Saskatchewan Learning, 2004; Alberta Learning, 2004).

**Recognizing the Neurological Basis of the Behaviour**

When working with students with FASD, it is essential to consider the neurological basis underlying behavioural and learning difficulties. While students with FASD may sometimes act in ways that seem irresponsible or unpredictable, as an educator it is important to remember that their behaviour is likely neurologically based. The student’s behaviour may be due to memory problems, their inability to problem solve effectively, or a response to becoming overwhelmed by stimulation (Alberta Learning, 2004). Teachers will more effectively meet the learning needs of students with FASD when they accept and understand that the student’s behaviour does not reflect willful noncompliance.
Chapter Four
Conclusion

Fetal Alcohol Spectrum Disorder is a life-long physical disability caused by the mother’s consumption of alcohol during pregnancy. FASD continues to be one of the leading causes of preventable birth defects and developmental delays in Canada (Canadian Paediatric Society, 1997). The fetus is vulnerable to damage from alcohol exposure for the entire duration of the pregnancy. The scope and severity of affects associated with FASD reflect the timing, quantity and duration of prenatal alcohol exposure. There is no safe amount of alcohol consumption for a pregnant mother.

The brain damage caused by prenatal alcohol exposure causes significant adverse effects on cognitive, behavioural, and emotional functioning. The primary disabilities associated with FASD result in a range of structural, physiological, behavioural and learning disabilities (Alberta Learning, 2004). Streissguth (1997) uses the term “secondary disabilities” to refer to disabilities that are not present at birth but are the result of the primary disabilities. Disrupted schooling, drug and alcohol abuse, victimization, mental health issues, and incarceration are all examples of secondary disabilities commonly experienced by individuals with FASD. The majority of individuals with FASD who have learning, behavioural, and cognitive difficulties resulting from prenatal alcohol exposure will not be easily identified because they will lack the characteristic facial features of FAS.

Diagnostic procedures for FASD have become more standardized in Canada with the mandated use of the 4-Digit Diagnostic code. However, FASD remains largely undiagnosed because of the need for more qualified diagnostic teams. Diagnosing FASD requires a multidisciplinary team of a physician with special training in FASD, a
psychologist, an occupational therapist, and a speech language pathologist. Diagnosis needs to become a governmental priority in order to accurately estimate the number of persons in Canada affected by FASD so that adequate social, educational, and health services are provided for this marginalized population of society. Early diagnosis will initiate appropriate interventions that may help mitigate the development of secondary disabilities. Diagnosis also provides the opportunity for the counselling and treatment of high-risk mothers, potentially preventing the recurring pattern of drinking while pregnant.

Fetal Alcohol Spectrum Disorder presents a significant challenge for educators. Teachers need to be knowledgeable about the indicators of prenatal exposure to alcohol and be cognizant that many of the children with FASD will not be formally identified. Knowing about FASD will help educators choose teaching methods, make environmental accommodations, and use behavioural strategies that will help children with FASD develop to their full potential. Educators who use strategies that are based upon a neurobehavioral approach, those who accept and understand that the student’s behaviour is not willful noncompliance but a physical disability, will be better equipped to make school a positive experience for a student with FASD.

Fetal Alcohol Spectrum Disorder will present different challenges at different stages of an individual’s development. While it is clear from the literature that interventions are necessary at all stages of development to optimize success, there is a general lack of research in the area of what constitutes an effective intervention. Caregivers, teachers, and frontline workers have largely developed the intervention strategies currently being used. Future studies that clinically evaluate the effectiveness of these interventions could encourage and promote best practice.
The literature acknowledges the need for careful planning and systematic transitioning through the life span but currently does not provide a detailed framework or guideline of support for alcohol-affected individuals. The disproportionate number of individuals with FASD who are currently incarcerated in prisons reflects the need to develop a more comprehensive transitioning and community support network. Unfortunately, too many individuals with FASD remain undiagnosed and are not receiving the support that they require because their disability remains largely invisible.

The goal of this study was to provide educators and caregivers with an overview of the complexity of Fetal Alcohol Spectrum Disorder and to provide meaningful intervention strategies. The success of individuals with FASD largely depends on having healthy, supportive relationships with people that understand the subtleties of neurological impairment, advocate on their behalf, and act as their external brain.
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Appendix A: Example of a Social Story: “Could you please repeat that?” (Gray, 2000)

Could you please repeat that?

When I do not understand something that is said to me, it’s okay to ask that person to repeat what they said.

I can try to look at the person and say, “Could you please repeat that? I don’t understand yet.” This is an intelligent thing to do.

The person will repeat what was said. It may help to hear it again.
<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Misinterpretation</th>
<th>Accurate Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noncompliance</td>
<td>• willful misconduct</td>
<td>• difficulty translating verbal directions into action</td>
</tr>
<tr>
<td></td>
<td>• seeking attention</td>
<td>• doesn’t understand</td>
</tr>
<tr>
<td></td>
<td>• stubborn</td>
<td></td>
</tr>
<tr>
<td>Repeats the same mistakes</td>
<td>• willful misconduct</td>
<td>• can’t link cause to effect</td>
</tr>
<tr>
<td></td>
<td>• manipulative</td>
<td>• can’t see similarities</td>
</tr>
<tr>
<td></td>
<td>• seeking attention</td>
<td>• difficulty generalizing</td>
</tr>
<tr>
<td></td>
<td>• bothering others</td>
<td></td>
</tr>
<tr>
<td>Doesn’t sit still</td>
<td>• willful misconduct</td>
<td>• neurologically-based need to move while learning</td>
</tr>
<tr>
<td></td>
<td>• seeking attention</td>
<td>• sensory overload</td>
</tr>
<tr>
<td></td>
<td>• bothering others</td>
<td></td>
</tr>
<tr>
<td>Doesn’t work independently</td>
<td>• willful misconduct</td>
<td>• chronic memory problems</td>
</tr>
<tr>
<td></td>
<td>• poor parenting</td>
<td>• can’t translate verbal directions into action</td>
</tr>
<tr>
<td>Doesn’t complete homework</td>
<td>• irresponsible</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• lazy, slow</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• unsupportive parent</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• memory deficits</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• unable to transfer what is</td>
<td></td>
</tr>
<tr>
<td></td>
<td>learned in class to a homework</td>
<td></td>
</tr>
<tr>
<td></td>
<td>assignment</td>
<td></td>
</tr>
<tr>
<td>Often late</td>
<td>• willful misconduct</td>
<td>• can’t understand the abstract concept of time</td>
</tr>
<tr>
<td></td>
<td>• lazy, slow</td>
<td>• needs assistance organizing</td>
</tr>
<tr>
<td></td>
<td>• poor parenting</td>
<td></td>
</tr>
<tr>
<td>Poor social judgment</td>
<td>• willful misconduct</td>
<td>• not able to interpret social cues from peers</td>
</tr>
<tr>
<td></td>
<td>• poor parenting</td>
<td>• doesn’t know what to do</td>
</tr>
<tr>
<td></td>
<td>• abused child</td>
<td></td>
</tr>
<tr>
<td>Overly physical</td>
<td>• willful misconduct</td>
<td>• hyper- or hypo-sensitive to touch</td>
</tr>
<tr>
<td></td>
<td>• deviancy</td>
<td>• doesn’t understand social cues regarding boundaries</td>
</tr>
<tr>
<td></td>
<td>• deviancy</td>
<td></td>
</tr>
<tr>
<td>Stealing</td>
<td>• deliberate dishonesty</td>
<td>• doesn’t understand concept of ownership over time and space</td>
</tr>
<tr>
<td></td>
<td>• lack of conscience</td>
<td>• immature thinking (finders keepers)</td>
</tr>
<tr>
<td></td>
<td>• doesn’t understand concept of</td>
<td></td>
</tr>
<tr>
<td></td>
<td>ownership over time and space</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• immature thinking (finders</td>
<td></td>
</tr>
<tr>
<td></td>
<td>keepers)</td>
<td></td>
</tr>
<tr>
<td>Lying</td>
<td>• deliberate dishonesty</td>
<td>• problems with memory and/or sequencing</td>
</tr>
<tr>
<td></td>
<td>• lack of conscience</td>
<td>• unable to accurately recall events</td>
</tr>
<tr>
<td></td>
<td>• sociopathic behaviour</td>
<td>• try to please by telling what they think you want to hear</td>
</tr>
<tr>
<td></td>
<td>• doesn’t understand concept of</td>
<td></td>
</tr>
<tr>
<td></td>
<td>ownership over time and space</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• immature thinking (finders</td>
<td></td>
</tr>
<tr>
<td></td>
<td>keepers)</td>
<td></td>
</tr>
<tr>
<td>Self-centredness</td>
<td>• selfishness</td>
<td>• only see the superficial or concrete level of social behaviour</td>
</tr>
<tr>
<td></td>
<td>• only cares about self</td>
<td>• doesn’t link cause and effect</td>
</tr>
<tr>
<td></td>
<td>• only cares about self</td>
<td></td>
</tr>
<tr>
<td>Volatile</td>
<td>• poor parenting</td>
<td>• exhausted from stress of trying to keep up</td>
</tr>
<tr>
<td></td>
<td>• aggressive nature</td>
<td>• extremely over-stimulated</td>
</tr>
<tr>
<td></td>
<td>• short-tempered</td>
<td></td>
</tr>
<tr>
<td>Inconsistent performance</td>
<td>• manipulating</td>
<td>• chronic memory problems</td>
</tr>
<tr>
<td></td>
<td>• sneaky</td>
<td>• inability to generalize learning from one situation to another</td>
</tr>
<tr>
<td></td>
<td>• not trying hard enough</td>
<td></td>
</tr>
</tbody>
</table>
Appendix B: Common Misinterpretations of Responses in Students with FASD (Evensen, 2000)

<table>
<thead>
<tr>
<th>Unmotivated</th>
<th>poor parenting</th>
<th>can’t project into the future and see what will happen</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>lazy</td>
<td>doesn’t connect today’s decisions with future opportunities</td>
</tr>
<tr>
<td></td>
<td>doesn’t care</td>
<td>doesn’t understand cause and effect</td>
</tr>
</tbody>
</table>