

**PARENTAL GUIDE TO FASD: A FOCUS ON A MULTIDISCIPLINARY
APPROACH AND COMMUNICATING WITH PROFESSIONALS**

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) can present many challenges for the individual and their family as they work towards accessing the appropriate supports. One major challenge in connecting with the appropriate professionals is communication and informing the support process from the perspective of the family. Families can have a large impact on creating positive outcomes and it is important that the voice of the family and the individual is heard throughout the support process. The purpose of this project is to conduct a literature review of various topics surrounding FASD, the need for many different professionals to be involved in the support of a child with FASD, and the importance of family involvement in the support of a child with FASD and the multidisciplinary team. The information gathered in the literature review was used to create a manual that families of children with FASD will be able to use as a source of information on FASD as well as guide for creating an effective working relationship with professionals involved in their child's support. The intent is to assist families in getting more involved in the many facets of the support process and hopefully lead to better outcomes for individuals with FASD.

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Chapter 1: Introduction

The effects of prenatal exposure to alcohol have been well document since 11 cases of fetal alcohol syndrome (FAS) were brought into public awareness in 1973 (Jones, Smith, Ulleland & Streissguth, 1973; Jones & Smith, 1973). Recently, fetal alcohol spectrum disorder (FASD) has become a widely accepted term that encompasses all clinical presentations and diagnosis resulting from prenatal exposure to alcohol (Chandrasena, Mukherjee & Turk, 2009). The umbrella term FASD includes such medical diagnosis as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), fetal alcohol effects, neurobehavioural disorder, and alcohol exposure (Green, 2007, Stratton, Howe & Battaglie, 1996). The impact of prenatal exposure to alcohol can lead to a wide range of presenting symptoms. These symptoms can present in a variety of ways depending on the individual and their situation. The number of reported cases of FASD is growing; which makes the topic of support and treatment increasingly important.

The actual prevalence of FAS it a difficult number to determine due to many factors such as there are a wide range of varying symptoms and a need for interdisciplinary assessment and diagnosis (May et al., 2009). This suggests that the prevalence rate for FASD would be even more difficult to determine given the less definitive diagnostic guidelines of the various conditions under the umbrella of FASD. Although there is still debate over the actual prevalence rate of FASD, there are some published studies that have attempted to determine the prevalence of FASD and this number can be looked at as an approximation. Chudley et al. (2005) report that the prevalence of FAS and FASD is one to three cases per 1000 live births and 9.1 per 1000

live births respectively in the United States. These rates are similar to the numbers reported by Sampson, Streissguth and Bookstein (1997) as they suggested the rate of FAS was between 2.8/1000 births and 4.1/1000 births. Although no national statistics were found on the prevalence of FASD in Canada, Chudley et al. reported similar rates in various smaller regions across the country. FASD is a condition that is occurring throughout the world, and Chandrasena et al. (2009) suggest FASD is the leading cause of preventable birth defects and development disabilities.

The effects of prenatal exposure to alcohol can cause physical, cognitive, and behavioural impairments that tend to present in a variety of different ways (Green, 2007). Physical characteristics include facial dysmorphia, growth deficiency, and central nervous system abnormalities (Chudley et al., 2005; Green, 2007). Cognitive characteristics involve impairments in basic cognitive functioning such as: difficulties with planning, organizing, attention, failure to learn from consequences, and memory deficits (Kodituwakku, Kalberg & May, 2001). As for behavioural issues, prenatal exposure to alcohol may lead to hyperactivity, emotional disorders, sleep disorders, aggression, inappropriate sexual behaviour, delinquency, and self harm (Green, 2007). Furthermore, individuals with FASD can exhibit a lack of inhibition, impulsivity, and poor judgement (Green, 2007). This broad range of symptomatology can lead to an individualized presentation of FASD that makes diagnosis and treatment difficult.

The diagnostic criteria for FAS are facial dysmorphia, growth deficiency, and central nervous system abnormalities (Green, 2007). The requirement of measurable physical abnormalities can often lead to a relatively straightforward diagnosis of FAS. However, there are many symptoms that can present as a result of prenatal exposure to

alcohol and they can present in varying degrees. The diagnostic process involves screening and referrals, a physical examination and differential diagnosis, a neurobehavioural assessment, and treatment and follow-up (Chudley et al., 2005). Chudley et al. (2005) highlight the importance of early diagnosis and also recommend that a multidisciplinary team is critical in appropriate diagnosis, treatment recommendations, and accessing useful resources. The diversity of diagnosis, symptoms, and treatment creates a need for a better understanding of the symptoms and interventions in order to create a more comprehensive knowledge base for helping affected individuals live full and productive lives.

Families are a major part of a person's life and this is no different for individuals with FASD. Streissguth (1997) suggests that the family of an individual with FASD need be an informed and active participant in an individual's support network. Families are often the first support that children have and this puts families in a critical position as it has been suggested that early diagnosis is a major contributor to successful support (Streissguth et al., 2004). The other key components to successful support for children with FASD is a collaborative support network involving families, teachers, school counsellors, community support workers, specialists, and administrators (Green, 2007; Streissguth, 1997). Although it has been reported that families and a collaborative and supportive approach to treatment can be beneficial for a child with FASD it is also important to note the challenges faced by parents and the family. For the purpose of simplifying terms, the words family and parents in this project will be synonymous with terms such as adoptive parents, foster parents, guardians, and primary caregivers. This is not meant to ignore the differences that exist between these different dynamics, but the

information provided on family supports is applicable to the primary support in the life of a child with FASD.

There is a large amount of information available for gaining a better understanding of FASD, but there are also many unknowns when it comes to the support of children with FASD. It is a difficult time for parents who are told that their child has a disability, and this difficulty is compounded when few answers and options are presented to parents. Whitehurst (2011) suggests that parents who have limited resources for care available and who deal with professionals who are not well informed are left feeling lonely, isolated, and often unable to cope. Streissguth et al. (1996) points out that the parents of children with FASD who have a limited understanding of the disorder, lack access to appropriate resources, and are fragile due to poor coping strategies putting their children at a greater risk for developing secondary disabilities. Whitehurst (2011) identified six themes that emerged from the stories of parent who identified that something was wrong with their child and the experience of parenting a child with a disability. The six themes are: first becoming aware that something is wrong, experiencing the disorder as a challenge, experiencing differences, experiencing emotional conflict, experiencing disability, and experiencing support. This study identified, from the parents perspective, that an early understanding and access to support is vital for positive outcomes for the child and the family.

The purpose of this project is put together an easy to read manual that brings together knowledge and resources concerning children with FASD for the purpose of educating families and highlighting the need for recognizing diverse symptomatology and individualized treatment options from a multidisciplinary perspective. Families are a

key component in the support of children with FASD; therefore, this manual will be geared towards informing families. The intent is to provide parents with a tool that not only contains information about FASD, but also information on communicating with professionals and putting in place the necessary supports for their children. The following is a literature review that will be the main source of information for the subsequent manual. The major topics covered in the literature review will be symptoms, diagnosis, treatment options, multidisciplinary approach, role of the family, and communicating with professional.

Chapter 2: Literature Review

The current literature on FASD highlights several physical, cognitive, and behavioural impairments that can result from prenatal exposure to alcohol (Green, 2007). These symptoms can present in varying patterns and severity, and can cause functional difficulties for the individual experiencing the symptoms. The diverse presentation of FASD symptoms can also be compounded by the symptoms of common comorbid disorders making diagnosis and treatment difficult. Many researchers allude to the importance of early and accurate diagnosis in the effective treatment of children with FASD (Chandrasena, Mukherjee, & Turk, 2009; Mutch, Peadon, Elliot & Brower, 2009; Peadon, Rhys-Jones, Bower & Elliot, 2009). The positive impact of recognizing symptoms early and understanding the support an individual with FASD requires makes it imperative for primary caregivers to be informed on the topic of FASD. The following literature review focuses on gaining a better understanding of physical abnormalities, impairments in social and executive functioning, common comorbid disorders, various treatment options, and the importance of involving a variety of professionals in the support of children with FASD.

Diagnosis/Defining the Terms

Fetal Alcohol Syndrome is a medical condition caused by the teratogenic effects of a mother consuming alcohol during pregnancy (Stratton, Howe & Battaglia, 1996). The impact of prenatal alcohol exposure has been shown to cause a variety of physical, cognitive, and behavioural impairments that the wide ranges of mild and severe effects and conditions have been placed under the relatively new umbrella term Fetal Alcohol Spectrum Disorder (Hoyme et al., 2005). Under the term FASD there are such conditions

as Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Birth Defects (ARBD), Alcohol-Related Neurodevelopment Disorder (ARND), Fetal Alcohol Effects (FAE), neurobehavioural disorder, and alcohol exposure (Green 2007; Hoyme et al., 2005; Stratton et al, 1996). Hoyme et al. (2005) point out that the Institute of Medicine's guidelines for the diagnosis of FAS, pFAS, ARBD, and ARND can be made with or without confirmation of maternal alcohol consumption during pregnancy. Fetal alcohol syndrome is diagnosed when the individual displays all diagnostic features of facial abnormalities, growth deficiency, and abnormal morphogenesis of the brain. A diagnosis of pFAS requires the presence of all three diagnostic categories but not the presence of all of the physical features. A diagnosis of ARBD involves the presence of structural abnormalities but the individual displays normal development and intelligence. Finally, ARND is characterised by the occurrence of a specific pattern of disordered behaviour even though the child displays normal growth and structural development. The varying effects and conditions included in the term FASD are important to understand, because they highlight the diverse impact that can result from maternal consumption of alcohol during pregnancy. For the purpose of clarification, the term FASD in this paper will be used to represent all conditions associated with FASD unless information is being presented that relates specifically to one term (i.e., FAS).

Common Misconceptions of Individuals with FASD

There are many myths surrounding FASD and the factors that surround this disorder. Understanding these myths and the information that actually surrounds the claim is critical in grasping the idea of FASD and stigma attached to this label. The

following is a breakdown of six common myths (Graefe, 2003). First, it is believed that all individuals with FASD have below average intelligence. Second, the maladaptive behaviours associated with FASD are the result of poor parenting and negative environment. Third, society gives up on individuals who have the label of FASD. Fourth, a child with FASD will grow out of this disorder as he or she develops into late adolescence and adulthood. Five, the diagnosis of FASD will negatively impact a child's development. Finally, it is not necessary to seek a diagnosis of FASD as there is no established and effective treatment approach. Many of these myths involve an element of truth, and some the opposite may be true.

Intelligence quotient. Prenatal exposure to alcohol has been found to cause varying degrees of brain damage that can negatively impact a fetus and child's development (Odishaw & Snart, 2005). Odishaw and Snart (2005) suggest that there are many factors that contribute to the brain damage experienced by children prenatally exposed to alcohol; therefore the developmental impact can vary quite greatly depending on the individual. A common result of the various types and degrees of brain damage experienced by individuals with FASD is reduced intelligence; however a below average intelligence quotient (IQ) is not completely synonymous with FASD. In a study conducted by Streissguth, Barr, Kogan and Bookstein (1996) the authors showed that in a group of 178 individuals with full FAS only 25 percent of the sample group were found to have an IQ below 70 (a score necessary for a diagnosis of Mental Retardation or an individual with a developmental delay). Also worth noting is that some of the individual were found to have an IQ within the average intelligence range. These findings suggest

that many individuals identified with FASD may have a below average IQ, but not necessarily all who have been prenatally exposed to alcohol.

Parenting. Parenting plays a large role in a child's development; however there are many behavioural, cognitive, and social concerns that can occur regardless of parenting. Streissguth et al. (2004) suggest that individuals with FASD who are raised in supportive homes may still experience behavioural difficulties. Furthermore, children with FASD are born with brain damage and many of them will experience symptoms of this brain damage throughout their life. This is not to say supportive parenting and access to appropriate supports does not positively impact the development of a child with FASD, but parenting is not directly related the child's behavioural concerns.

FASD label and giving-up on the individual. There are many challenges faced by individuals diagnosed with FASD and many faced by the support system around them. In spite of these challenges there is a significant amount of support for those diagnosed with FASD. Strade et al. (2009) conducted a study examining the cost and financial support provided to individuals with FASD. They found that costs related to medical services, social services, education, out-of-pocket cost, and cost due to productivity loss accounted for a significant cost. The average annual cost at an individual level associated with FASD was approximately \$21,642, and the annual cost to Canada for those individuals with FASD aged 0-53 years is approximately \$5.3 billion. Although this is just a reflection of the amount of financial support provided to individuals with FASD it highlights the level of support that is given to those diagnosed with FASD.

Outgrowing FASD. Symptoms of FASD experienced by children with FASD may change over time, and they may find more appropriate ways to manage their

symptoms; however, many symptoms and secondary disabilities persist into adulthood (Chudley, Kilgour, Cranston & Edwards, 2007). In a longitudinal study conducted by Streissguth et al. (2004) the authors found that the life time prevalence of disruptive school experience was 61 percent, troubles with the law was 60 percent, inappropriate sexual behaviour was 49 percent, and drug and alcohol related problem was 35 percent. In addition, adults with FASD are at a higher risk for mental illness such as depression and anxiety related disorders (Chudley et al., 2007; Hellemans, Sliwowska, Verma & Weinberg, 2010). Streissguth et al. suggested that symptoms of FASD are exacerbated by poor upbringing and late diagnosis.

Negative impact of FASD diagnosis. Early diagnosis has been suggested as one of the major catalyst in improved development and outcomes for children with FASD (Streissguth et al., 2004). A diagnosis of FASD allows for greater access to interventions, and financial and community support resources. Furthermore, Streissguth et al. (2004) suggest that early diagnosis and increased access to resources has a significant impact on decrease the impact of secondary disabilities such as unemployment, disrupted school experience, mental health problems, trouble with the law, and inappropriate sexual behaviour. Chudley et al. (2005) points out that the proper support of children with FASD requires many professionals and various expertise to be involved and that this multidisciplinary approach is more appropriately put together when a child is diagnosed with FASD. At times a label can seem like a negative thing; however, in the case of FASD a diagnosis can be a major piece of the developmental and treatment puzzle.

No “real” treatment option. There are diagnosable conditions that have no clear treatment approach; however, there are many treatments and factors that contribute to

better outcomes. In regards to FASD, there are many intervention approaches that have been shown to be effective in the treatment of FASD. These interventions include psycho-educational (Coles, Kable & Taddeo, 2009), psychosocial (O'Connor et al., 2006), psychopharmacological (O'Malley, Koplin, & Dohner, 2000), and neuropsychological profiling (Mattson et al., 2010a; Mattson et al., 2010b). In addition, it has been shown that individual with FASD benefit greatly from early diagnosis and a supportive upbringing (Streissguth et al., 2004). Although the treatment path for individuals diagnosed with FASD is not clear and straightforward due to the diversity of physical, behavioural, and cognitive symptoms, there are many interventions and strategies that are worthwhile and can contribute greatly to positive outcomes.

Physical Abnormalities Associated with FAS

Prenatal exposure to alcohol has been associated with physical abnormalities such as facial dysmorphia, growth deficiency, and central nervous system abnormalities (Green, 2007). Evidence of these physical abnormalities are required for a diagnosis of FAS, but can be absent in other disorders and conditions within the FASD spectrum as mentioned above. Facial dysmorphia is characterized by three main facial features: palpebral fissure length, philtrum smoothness, and upper lip thinness (Astley & Clarren, 1995; Astley & Clarren, 2001). Palpebral fissure length is the distance between the endocranion (the inner corner of the eye) and the exocanthion (the outer corner of the eye); which concerning individuals with FAS this distance is shorter than an individual without FAS (Astley & Clarren, 2001). The philtrum furrow is the vertical groove that extends from the middle of the upper lip to the bottom of the nose. Regarding individuals with FAS this area between the upper lip and the bottom of the nose is smooth (Astley &

Clarren, 2001). Finally, the thinness of the upper lip is reflected by limited surface area of the exposed red portion of the upper lip known as the vermilion border (Astley & Clarren, 2001). All three of these facial features are required to confirm the diagnosis of FAS and are the unique features of FAS as the presence of growth deficiency and CNS abnormalities is not definitively linked to prenatal exposure to alcohol.

Although the facial features associated with FAS may be the most identifiable characteristics, physical growth and brain development abnormalities may have the largest impact on those prenatally exposed to alcohol. Sokol and Clarren (1989) suggest that deficient prenatal and postnatal growth is characterized by a length and height measurement that is below the 10th percentile when age is controlled for. In regards to brain abnormalities, autopsies and magnetic resonance imaging (MRI) studies have shown that individuals with FAS have microcephaly (circumference of the head is smaller than normal) and overall reduction in the size of the brain (Mattson et al., 2006; Riley & McGee, 2005). Specifically, Mattson et al. (2006) found that children with FAS have a reduction in the volume of the cerebrum, basal ganglia, and diencephalon. Furthermore, Riikonen, Salonen, Partanen and Verho (1999) showed that volume of the left hippocampus was smaller than the right hippocampus in children with FASD. These structural abnormalities have been associated with many cognitive impairments and behavioural problems that can present in varying degrees (Niccols, 2007).

Social and Adaptive Functioning Associated with FASD

Impairments in social and adaptive functioning have been shown to be present in children prenatally exposed to alcohol. Whaley, O'Connor, and Gunderson (2001) conducted a study comparing children prenatally exposed to alcohol to a non-exposed

clinical group of children. The study utilized Vineland Adaptive Behaviour Scales (VABS) which was given to caregivers for the purpose of rating a child in the domains of communication, daily living skills, and socialization. In the two groups of children assessed in this study there was no significance found between the groups in any of these domains. However, when the results of individuals of the same age were compared there was a significant difference between exposed children and non-exposed children with the biggest difference being in the domain of socialization. This suggests that children with FASD may be at risk for impairments in social and adaptive functioning and impairments may increase with age.

Social cognition. It has been shown that children prenatally exposed to alcohol display impairments in social functioning as rated by caregivers (Whaley, O'Connor, & Gunderson, 2001). However, McGee, Bjorkquist, Price, Mattson, and Riley (2009) identified that little is known about the social cognitions of this particular group of children. The goal of their study was to assess patterns in social information processing using Cricks and Dodge's reformulated six-stage model. The study presented vignettes and then used the six steps of analysis to ask the children details about the story and different ways they may react in situation presented in the story. The results showed that the children in the alcohol exposed group demonstrated difficulties in all six steps of the social information processing interview when compared to the matched control group. Specifically, the alcohol exposed children recalled and encoded less relevant information, evaluated competent response as ineffective, evaluated inept responses more favourably, generated a higher proportion of aggressive responses, provided fewer pro-social goals, and were less likely to repeat a competent response with appropriate tone of voice and

eye contact during the enactment step. The results of this study suggest possible mechanisms for previously observed social difficulties for children prenatally exposed to alcohol.

Moral development. Children who have been prenatally exposed to alcohol have been shown to be morally stunted compared to children who were not prenatally exposed to alcohol (Nash et al., 2006; Rasmussen, Talwar, Loomes, & Andrew, 2008). Nash et al. (2006) conducted a study comparing the results of the Child Behavioural Checklist (CBCL) for children who have been diagnosed with Fetal Alcohol Syndrome (FAS) or Alcohol-Related Neurodevelopmental Disability (ARND) with children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and children controls. They found that the endorsement rate for the items “lying and cheating” and “no guilt” were higher for children with FAS/ARND than controls, and “lying and cheating” was also higher than children with ADHD. In addition, Rasmussen, Talwar, Loomes, and Andrew (2008) conducted an experimental research study targeting lying behaviour in children (between 4 and 8 years of age) diagnosed with an alcohol related disorders. The children in the FASD group were compared to same aged children in a control group. The results showed that the children in the FASD group were found to lie significantly more than the control group. Furthermore, the FASD group was shown to be more effective at concealing their transgression and maintaining semantic leakage control than the non-FASD control group. The results from both of these studies suggest that prenatal exposure to alcohol can result in stunted moral development for the affected individual.

Executive Functioning and Individuals with FASD

Rasmussen (2005) suggests that impairments in executive functioning (EF) have been implicated in FASD. She defines executive functioning as the conscious control of higher order psychological processes involved in goal oriented behaviour. These higher order processes include: planning, organized searches, inhibition, working memory, and fluency (Rasmussen). Green et al. (2009) used the Cambridge Neuropsychological Tests Automated Battery (CANTAB) to assess executive functioning and working memory capabilities of children with FASD compared to a control group. Between the two groups they found a very strong difference on the spatial working memory task where the FASD committed significantly more errors than the control group. Other tasks that yield significant difference included reaction time in one and five choice tasks, decision time on *Match to Sample Visual Search (MTS)*, and number of problems solved in the minimum number of moves on the *Stocking of Cambridge (SOC)* task. In all of the aforementioned tasks the control group outperformed the FASD group. The results of this study show that children with FASD show measurable deficits in executive functioning, and that task requiring the use of spatial working memory and strategy prove to be especially difficult for children with FASD.

Another study sought to identify structural brain abnormalities in areas supporting spatial working memory that may contribute to deficits identified in children with FASD (Spandoni et al., 2009). They used functional magnetic resonance imaging (fMRI) to assess blood oxygen level dependent (BOLD) response of children with FASD and age-sex matched controls on spatial working memory tasks and vigilance control task. In terms of performance no statistical difference was found between the groups on task

accuracy or reaction time; however the control group was slightly faster than FASD group on vigilance tasks. Furthermore, no structural abnormalities or brain volume discrepancies were observed between the two groups. The author point out that this is not conclusive evidence that structural abnormalities do not exist, and that the lack of evidence could be due to the small sample size. The study results did show that the FASD group displayed significantly greater BOLD activation during spatial working memory task relative to vigilance tasks when compared to matched controls. As the task became more mentally taxing the FASD group did not differ in performance, but did show heightened activation of relevant regions of the brain. This suggests that an increase in BOLD response for the FASD group is a compensatory mechanism and greater activation may be required to meet the challenging demands of spatial working memory tasks.

Learning and memory. Deficits in learning and memory are a commonly reported result of prenatal exposure to alcohol. Willford, Richardson, Leech, and Day (2004) conducted a longitudinal study where mother and child were assessed at the child's birth and then administer the Children's Memory Scale at 14 years of age. They found that children with low to moderate gestational exposure to alcohol displayed difficulties in encoding/storage processing. Specifically, prenatal alcohol exposure was significantly related with below average performance on the Verbal Delay Index; which was shown to be due to impaired performance of long-term recall of word pairs. Overall, this study showed that prenatal exposure to alcohol can cause deficits in learning that are specific to the verbal domain. Similarly, Roebuck-Spencer and Mattson (2004) found that children with heavy prenatal exposure to alcohol learned significantly less verbal information than their matched controls. However, the FASD group performed as well as

controls on verbal learning test that lacked implicit semantic categories. The findings from both of these studies suggest that prenatal alcohol exposure can lead to deficits in learning and memory, specifically in the domain of verbal learning.

Concept formation. An individual's capacity to develop mental categories for objects, events, and ideas is a critical element for abstract thought and problem solving in everyday life. McGee, Schonfeld, Roebuck-Spencer, Riley, and Mattson (2008) designed a study aimed at evaluating the ability of a child prenatally exposed to alcohol to form concepts. They conducted two experiments. The first one utilized the Wisconsin Card Sorting Test (WCST); which is designed to indicate how well an individual incorporates feedback into critical thinking strategies. The second experiment utilized the Card Sorting Test (CST) from the Delis-Kaplan Executive Functioning System (D-KEFS); which is an evaluation of verbal and nonverbal abilities as well as verbalization of principles. The results of the WCST showed that the group prenatally exposed to alcohol performed poorer on all comparisons including: percentage of conceptual level responses, percentage of *perseverative responses*, percentage of total errors, percentage of *perseverative errors*, and percentage of *non-perseverative errors*. These findings suggest that children prenatally exposed to alcohol experience difficulties in flexibility and evaluation of outcomes, and concept attainment. In the CST experiment the children in the alcohol exposed group were less able than controls to sort cards correctly and scored lower on their description of the sorts. Furthermore, the alcohol exposed group were less effective at inferring similarities in cards and drawing higher order inferences. In the structured sorting condition they provide poorer descriptions and more incorrect and repeated responses suggesting poorer attention to relevant cues. The results of this study

indicate that children prenatally exposed to alcohol experience difficulty in identifying and formulating concepts, which decreases their ability to problem solve.

In a social problem context it has been shown that children prenatally exposed to alcohol have poorer social problem solving skills than their non-exposed peers (McGee, Fryer, Bjorkquist, Mattson, & Riley, 2008). McGee et al. administered the Social Problem Solving Inventory, Revised (SPSI-R) to prenatally alcohol exposed children and non-exposed controls. They found that when compared to the non-exposed group the exposed group showed significant impairments in social problem solving, and were more likely to approach problems with a pessimistic orientation as well as having a low frustration tolerance when approached with difficult tasks. The study also involved a structured behaviour rating scale to be completed by parents with the purpose of measuring behavioural manifestations of executive function in their children. It was found that prenatally alcohol exposed children were rated as having more difficulty controlling their behaviour through inhibiting behavioural response, controlling emotions, and shifting between tasks. Also noted were impairments in working memory, initiating and planning tasks, and organization. Both studies indicated prenatal exposure to alcohol can lead to cognitive impairments required for effective problem solving skills.

Inattention. Deficits in attention are one of the hallmark characteristics of children who have been prenatally exposed to large levels of alcohol. Mattson, Calarco, and Lang (2006) suggest that one concern about previous research on identifying the presence of attention deficits in children with FASD is that there are many domains within the concept of attention. They designed a study that evaluated children with heavy prenatal exposure and non-exposed children utilizing a paradigm comprised of three

conditions: visual focus, auditory focus, and auditory-visual shift in attention. The ultimate goal of the study was to assess whether prenatal exposure to alcohol disrupts an individual's ability to shift the focus of attention between sensory modalities. They found that in the *focussed attention* condition the FASD group responded slower and less accurately than the control group; however differences in response time was not the same for visual and auditory stimuli. The FASD group was slower than the control group on all time intervals concerning visual stimuli, and they were only slower on the longest time interval concerning auditory stimuli. This suggests that children with FASD experience difficulty maintaining attention over long intervals. In the *shift of attention* condition where participants were required to respond alternately to visual and auditory stimuli it was found that the FASD group was similar to the control group on accuracy, but demonstrated slower reaction times. Overall, the findings in this study suggest that prenatal exposure to alcohol can cause deficits in the exposed child's reaction time to visual and auditory stimuli.

Mick, Briederman, Faraone, Sayer, and Kleinman (2002) found that prenatal exposure to alcohol increased a child's risk of developing ADHD by two and half times. The above research study shows that there is an attention deficit component to FASD, but Kooistra, Crawford, Gibbard, Rampage, and Kaplan (2010) suggest there is still ambiguity in regards to the nature of these deficits and whether they differ from those found in attention-deficit-hyperactivity disorder (ADHD). Kooistra et al. sought to examine sustained attention and inhibitory control in children with FASD, ADHD, and children with neither. They found that on a *continuous performance task* the FASD group and the ADHD group showed greater declines in task performance over time and were

more prone to errors than was the control group. Furthermore, on the task involving variable time intervals the FASD group performance was lower than the ADHD group on tasks transitioning from a *slow event rate* to a *fast event rate*. The authors suggest that the variation in susceptibility to slow and fast pacing of task transitions could be a distinct differential diagnosis markers that characterizes the different attention profiles in children with FASD compared with children with ADHD.

Common Conditions that Co-occur with FASD

As mentioned above, FASD and ADHD have some similarities in symptoms and are two diagnoses that commonly accompany one another (Mick et al., 2002). However, there are many disorders and symptoms that co-occur with FASD, and the symptoms of FASD need to be differentiated from the symptoms of other disorders in order to better understand an individual's presenting symptoms. In a study aimed at assessing psychiatric disorders found in children prenatally exposed to alcohol it was found that 61% of the sample met the criteria for a mood disorder. Specifically, 35% of the sample met the criteria for bipolar disorder and 26% met the criteria for major depressive disorder or adjustment disorder with depressed mood. This sample was taken from a clinical setting and the results showed that the large majority of children a diagnosis of FASD comorbid with bipolar disorder were inpatients and this may have contributed to the high rate of comorbidity. Prenatal exposure to alcohol has also been associated with diagnoses of anxiety disorder (Hellemans, Silwowska, Verma & Weinberg, 2010), epilepsy and seizure episodes (Bell et al., 2010), and alcohol abuse related disorders (Baer et al., 2003; Sher, Grekin & Williams, 2005). The presence of a comorbid disorders

complicates the presentation of FASD; therefore effectively identifying dual diagnoses is crucial in creating an effective treatment plan.

Interventions Utilized in the Support of Children with FASD

Many researchers allude to the importance of early and accurate diagnosis for the effective treatment of children with FASD (Chandrasena, Mukherjee, & Turk, 2009; Mutch, Peadon, Elliot, & Brower 2009; Peadon, Rhys-Jones, Bower, & Elliot, 2009). However, Chandrasena et al. suggest that topic of diagnosis in FASD remains controversial and even with the large body of literature diagnosis continues to be difficult. For the purpose of this paper the literature on FASD diagnosis will not be discussed, but the topic will be a suggestion for the proposed educational manual. There are many intervention strategies that are being utilized in the treatment of FASD such as pharmacological, behavioural, psychological, psycho-educational, psychosocial interventions (Burd & Christensen, 2009; Chandrasena et al.; Peadon et al.). Some of the literature on these interventions will be discussed below as well as the effectiveness and potential benefit of neuropsychological profiling.

Psycho-educational. Many of the aforementioned studies document the cognitive and behavioural deficits experienced by children who have been prenatally exposed to alcohol. Coles, Kable and Taddeo (2009) designed a study that focused on the efficacy of psycho-educational intervention that targeted the math skills of children diagnosed with FASD. The study involved randomizing the placement of prenatally alcohol exposed participants into a math intervention group or a psycho-educational treatment contrast groups. Both groups were enrolled in the psycho-educational workshops focused on training the care-givers and teachers of a child on FASD and the impact it can have on a

child. In addition, the children in the math group were put through a 6 week math intervention tailored specifically to their individual needs based on a pre-intervention neurodevelopment assessment. Based on satisfaction scales, behavioural scales (Child Behavior Checklist and Teacher Report form), and pre-test/post-test standardized math test significant results were found. Parent satisfaction ratings were high in both groups, significant reductions in behavioural disturbance were found in both groups, and gains in intellectual ability were significantly higher in the math intervention group than in the contrast group. The researchers suggest that this is just an initial step in developing a treatment for children prenatally exposed to alcohol, but it appears that children with FASD who struggle academically may benefit from tailored and individualized instruction.

Psychosocial. As shown above by Whaley, O'Connor, and Gunderson (2001) children with FASD are at greater risk for impairments in social and adaptive functioning. O'Connor et al., (2006) conducted an experimental study aimed at identifying the effectiveness of child friendship training (CFT) for children who have been prenatally exposed to alcohol. There were one hundred children involved in the study where half were assigned to the CFT group and the other half were assigned to a delayed treatment control group (DTC). The treatment condition was facilitated by clinical psychology interns and involved instruction on simple rules of social behaviour through modeling, rehearsal, performance feedback during treatment, rehearsal at home, homework assignments, and coaching by parents during play with peers. The groups were assessed at baseline, post-treatment (12 weeks), and at a three month follow-up. O'Connor et al. found a significant difference between the two groups on increased social

skills and reduced problem behaviours. Furthermore, the improvements shown in the post-test were retained at the three month follow-up. However, the follow-up period may need to be longer to fully assess learning, and the study only included children with a verbal IQ of 70 or above to ensure that didactic portion of treatment was understood. Further studies may be needed to show a more comprehensive treatment option for children with FASD struggling with social deficits.

Psychopharmacological. In a pilot study O'Malley, Koplin, and Dohner (2000) showed a greater positive response through the use of dextroamphetamine (psychostimulant) over methylphenidate (psychostimulant) in the FAS and FAS co-occurring with ADHD subtypes. However the study involved a small clinical group of children, the length of treatment was not outlined, and "positive response was not defined. Conversely, Doig, McLennan, and Gibbard (2008) conducted a similar study in an attempt to show the efficacy of psychostimulants in the treatment of ADHD that is co-morbid with FASD. Participants taking a methylphenidate product were shown to have improvements on score of hyperactivity/impulsivity and opposition/defiance, but no improvements or changes were noted on scores of inattention. Similar to the study done by O'Malley et al., the sample size was small and did not capture a full range of FASD severity in terms of brain damage/ dysfunction and growth retardation. Both studies showed psychostimulants to yield minimal improvements in the symptomatology of FASD and both produced conflicting results. More research is need in the area of psychopharmacology as a viable treatment option for children with FASD.

Psychosocial and psychopharmacological. One common element of FASD is the co-occurrence of ADHD (Mick et al., 2002); however the symptoms of both can

present differently (Kooistra et al., 2010) and may require different interventions. Frankel, Paley, Marquardt, and O'Connor (2006) sought to identify the efficacy of neuroleptic medication and stimulants paired with Children's Friendship Training (CFT) in the treatment of FASD. The involvement of CFT was to address the need for children with FASD to develop positive peer relationships and the necessity of having parental involvement in this process (Bhavnagri & Parke, 1991). The assessment was based a Social Skills Rating System (SSRS) which included 7 items, but only assertion, self-control, problem behaviour measures were relevant to friendships. The questionnaire was completed by both parents and teachers and the results yield significant differences between the treatment group (CFT) and the delayed CFT group (control). Frankel et al. (2006) found that children with FASD who are prescribed neuroleptic medication showed significant improvements on all measures of the scale when compared to children with FASD who were prescribed stimulants. Although, the factors such as dose and additional medications were not fully controlled for this study suggests an alternative treatment that may differ from effective treatments for ADHD. Furthermore, FASD and ADHD have been shown to co-occur, but slight difference may suggest a need for practitioners to treat both disorders separately.

Neuropsychological Profiling. One major part of the effective treatment of FASD is obtaining an accurate diagnosis, which is not a black and white process given the diverse presentation of symptoms (Churdley et al., 2005). In a study by Mattson et al. (2010b) the researchers utilized data from two sites (San Diego State University and Folkhalsan Research Center) of a multisite study (Mattson et al., 2010a) and a diverse range of neuropsychological test batteries. The participants were separated into four

groups based on the presences or non-presences of the physical features of FASD, or a complete absence of symptoms (control groups). The participants were assessed using a number of neuropsychological test batteries. The results indicated that specific neuropsychological tests could be utilized in distinguishing children exposed prenatally to alcohol who display physical symptoms and those who do not. Furthermore, the resulting profile can be used to identify those children prenatally exposed to alcohol who do not display the physical symptoms from non-exposed controls. Mattson et al. suggest that the profile is more accurate than classifying based on IQ alone. The profile consists of tests of executive function, attention, spatial learning and memory, fine motor speed, and visual motor integration. The researchers suggest that more research is needed on performance on spatial tasks and the study was limited by the measures chosen for inclusion in the test battery and useful measures may have been excluded. Despite possible imperfection this study provides a stepping stone towards more accurate profiling of individuals prenatally exposed to alcohol and hopefully more effective treatment.

Multidisciplinary Approach and the Support of Individuals with FASD

The diverse symptomatology of FASD and the need for individualized treatment suggests that a multidisciplinary approach be utilized in the support of individuals with FASD. Chudley et al. (2005) highlighted that a multidisciplinary approach involves professionals and various members of a support network working together in supporting an individual with FASD. Furthermore, this approach is crucial in the process of early and appropriate diagnosis, formulating effective treatment recommendations, and ensuring access to appropriate resources. Chudley et al. recommends a multidisciplinary

team be comprised of a coordinator for case management, physician specifically trained in FASD diagnosis, psychologist, occupational therapist, and speech-language pathologist. In addition, other key components to an effective support team include families, teacher, school counsellors, and community support workers (Green, 2007; Streissguth, 1997). There has been little research focused on the use of a multidisciplinary approach in the support of individuals with FASD; however, there has been research on applying this approach in the support of individuals with ADHD.

In a review of 391 case notes of children diagnosed with ADHD, Parr, Ward and Inman (2003) found that the communication between families, schools, and professionals was either lacking or not happening. The authors suggest that this lack of communication inhibits the proper support of children with ADHD as a full range of information is not gathered, and one professional (i.e., paediatrician) is often assuming the role of other professionals (i.e., psychologist). Hazelwood, Bovingdon and Tiemens (2002) proposed that a strong approach to utilizing a multidisciplinary team would be assigning a clinical case manager to children with ADHD that could inform the child and family, involve the necessary professionals, and access appropriate community resources. No research articles were found that specifically focussed on the effectiveness of a multidisciplinary approach to support; however, many sources suggested there is a need for this type of approach in the support of children with FASD and ADHD (Chudley et al., 2005; Green, 2007, Hazelwood et al., 2002; Parr et al., 2003; Steer, 2005; Streissguth, 1997; Streissguth et al., 2004). Streissguth et al. (2004) points out that families, communities supports, and physicians working together reduces the risk of adverse outcomes for a

children with FASD and better ensures they are raised in a long-standing, stable, and nurturing environment.

Communication Between Families and Professionals

Due to the unique support needs of children with FASD it is necessary for families and professionals to effectively communicate. A large portion of the communication responsibility falls on the parents of a child with FASD as many professionals need to be involved and often parents are left to coordinate this support (Streissguth, 1997). It is important for parents to be informed and to actively participate in a child's support (Streissguth et al., 2004). This requires the parent to gain an understanding of their child's disability, establish their role, and communicate their needs and the needs of their child to the appropriate professionals. The following is a breakdown of the suggested role of the family with a child with FASD, and ideas for appropriate communication with schools and professionals.

Role of the family. The family of a child with FASD can play an integral role in reducing the risks caused by prenatal exposure to alcohol. Streissguth et al. (2004) showed that 80% of children diagnosed with FAS or FAE do not live with their biological parents. This means that 80% of children affected by FASD live in foster and adoptive parent situations. Although, Streissguth et al. suggest that unstable and a less nurturing living arrangements may contribute to adaptive behaviour issues the opposite has also been suggested to have a positive impact of life outcomes. The importance of early diagnosis has also been stressed in terms gaining an understanding of the disorder and accessing necessary supports. Therefore, children with FASD who are raised in a stable and nurturing environments, and who have received an early diagnosis more

effectively transition to adolescence and young adulthood and form closer relationships to their family (Streissguth et al., 2004).

Family environment plays a key role in the positive development of a child with FASD; however, there are specific family characteristics and roles that contribute to a stable and nurturing environment. Bailey (2007) suggests that families of children with developmental disabilities need to educate clinicians and become involved in various support groups. Furthermore, parents need to play the role of an advocate for their child and be directly involved in their treatment (Bailey, 2007; Streissguth, 1997). It has been shown that families who are highly involved in the support of a child with a developmental disability produce better outcomes for the child than do families who are not involved (Neely-Barnes, Graff, Marcenko & Weber, 2008). Family-centered early intervention has been suggested as the direction of choice for the support of children with FASD given the positive impact a family can have (Bruder, 2000; Olson, Oti & Beck, 2009); however, there are research-to-practice gaps which include training for the families as well as proper communication between families and professionals.

Communicating with professionals. The idea of families collaborating with professionals as a recommended practice in the support of children with disabilities has been around for quite some time. Bruder (2000) suggest that most families would not choose to have a child with disability, but most professionals choose to be involved in child intervention as a job, career, or avocation. Furthermore, Bruder proposes a concept of early intervention that is family-centered approach involving a collaborative partnership between family and professionals that is rooted in the philosophies of the family. One of the central problems with the development of this relationship is the

failure to create collaborative, trusting, value focussed, and empowering relationships between families and professionals that leads to efficacious service delivery (Harry, Rueda & Kalyanput, 1999). Blue-Banning et al. (2004) suggest that operationally families and professionals do not know what to expect of each other making mutual respect and trust more difficult to establish.

In a study involving 33 focus groups, Blue-Banning et al. (2004) sought to establish indicators of professional behaviour that would facilitate a collaborative partnership. The focus groups were comprised of family members with and without children with a disability, and service providers and administrators. The resulting qualitative data yielded six broad categories: communication, commitment, equality, skills, trust, and respect. Communication from professionals should be free from jargon and resources should be openly shared. Families should be open in their communication, and come to appointments prepared with relevant questions. Families want to know that professionals are committed to the support of their children and the professional relationship is valued. Furthermore, there must be equality in the relationship and sense of harmony. Family members appreciate knowledgeable professionals who show a willingness to learn and adapt. Both parents and professionals emphasized the importance of being able to rely on each other, and the interaction will be held in confidence and have a sense of safety. Finally, parents have an expectation that their children will be valued as individuals and interactions will be professional in nature; whereas professional desired interactions from families to be non-judgmental and respectful of their responsibilities. These themes and recommendations were not shown to contribute to an

effective collaborative relationship between families and professionals, but they do serve as a guideline for what both parties expect in terms of a professional relationship.

Communicating with schools. The relationship between families and schools is crucial to a child's development given that a child spends the majority of his or her life in a family and school environment. This relationship becomes especially important when supporting children with developmental disabilities who have unique needs and face unique challenges. Carr et al. (2002) suggests a need to incorporate elements of Positive Behaviour Support (PBS) in a school environment. Positive behaviour support includes "all those skills that increase the likelihood of success and personal satisfaction in normative academic, work, social, recreational, community, and family settings" (p. 4; Carr et al.). This approach requires professionals to involve all relevant stakeholders (especially families) in the planning, implementation, and evaluation of proposed supports in the school. Carr et al. asserts that PBS is a value driven approach that focuses on collaboration in the support of children with unique developmental concerns. Parental involvement in a child's education has been shown to lead to significant positive outcomes for the child (Fanruzzo, McWayne, Perry & Childs, 2004).

Fanruzzo, McWayne, Perry and Childs (2004) conducted a study that assessed the significance of Home-Based family involvement, School-Based involvement, and Home-School Conferencing and overall outcomes for the child. Home-Based family involvement refers to the education related activities that are done in the home (i.e., reading to a child). School-Based involvement refers to educational activities that are done in the classroom, and Home-School Conferencing refers to the collaboration between parents and teachers. It was shown that Home-Based involvement yielded the

largest benefits to overall outcome of the child. The benefits included greater motivation to learn, increased attention and task persistence, improved receptive vocabulary skills, and lower conduct problems. The authors suggested that Home-School Conferencing was expected to yield more significant results and that cultural and socioeconomic barriers may have impacted the results. Minke and Anderson (2005) suggest that one key factor to effective family-school collaboration is respect and understanding of the roles that all parties play in the child's development. Although, the above information is not based on families of children with FASD the related elements to a child's development apply, and Carr et al. (2002) points out the challenges faced by a child with a disability only increases the need for family-school collaboration.

Conclusion

Fetal Alcohol Spectrum Disorder is a preventable developmental disability that can have a lifelong impact on a child. The symptoms of FASD are extremely diverse and there are many disorders that commonly co-occur with FASD. The wide range of possible symptomatology makes a straightforward diagnosis and treatment plan difficult. Although a clear treatment plan for FASD may not be available, there are factors that can contribute to better life outcomes for children with FASD. These factors may include a supportive living environment (Streissguth et al., 2004), early diagnosis (Chudley et al., 2005; Streissguth et al., 2004), and a multidisciplinary approach to treatment and support (Chudley et al., 2005; Green, 2007). A multidisciplinary approach to treatment involves families and professionals effectively working together to meet the unique needs of the child. This may seem like a simple a straightforward concept; however there are communication barriers that need to be overcome. It is the hope of the following manual

that an outline (largely based on the information above) for effective communication between parents and professional can be established.

Chapter 3: Methods

Purpose of Manual

The purpose of the above literature review and the subsequent manual is to provide a comprehensive information package to families that outlines current knowledge in the area of FASD, and highlights the importance of family involvement in a multidisciplinary approach to treatment and support. The sections included in the following manual are prevalence, physical symptoms, cognitive and behavioural symptoms, diagnosis, comorbid disorders, interventions, common misconceptions, multidisciplinary approach, role of the family, and families communicating with professionals. The final sections of the manual will be focussed on communication between families and professionals, and resources and additional supports. Furthermore, it is also the intent to focus on benefits of involving informed families and many various professionals in the support of children with FASD. The title of the manual is “Parental Guide to FASD: A Focus on a Multidisciplinary Approach and Communicating with Professionals” and it is based on existing literature and information on FASD and other relevant and applicable areas. The main objective of this manual is to educate parents and ensure that proper supports are provided to individuals with FASD.

Information Collection

A major focus of this project has been on reviewing the available literature on FASD, utilizing a multidisciplinary approach, establishing the role of the family, and ensuring proper communication between families and professionals. This review of the literature has involved a search of major electronic journal databases offered at the University of Lethbridge library. Databases accessed were: PsycINFO, PsycARTICLES,

Medline, Academic Search Premier, Science Direct, Wiley Online Library, Pubmed, and Google Scholar. The search terms that were utilized included: fetal alcohol syndrome, fetal alcohol spectrum disorder, prenatal exposure to alcohol, prevalence, history, diagnosis, physical symptoms, behavioural symptoms, cognitive symptoms, social and adaptive functioning, intelligences quotient, lifespan, treatment, families, role, family-centered, school, education, community supports, multidisciplinary approach to treatment, developmental disabilities, family and professional communication. In addition, references lists of current peer reviewed articles and literature (within a 10 year span) were searched for relevant resources. Relevant sources were accessed by putting the titles into the Google Scholar search engine available through the University of Lethbridge library. Finally, information was gathered from existing manual focussed on FASD and established supports that provide information to families and individuals.

Putting the Information Together

The information gathered was put together in a logical and comprehensible format in order to maximize the educational value of the proposed manual. Each section is separated into easy-to-read sections that allow the average reader to understand the information. Efforts were taken to speak with supervisors and professionals to gain information on creating and effectively organized manual. The intent will be to submit this manual to various publishers for the purpose of having the manual published and made available to families and community support agencies. The goal for the published manual will be to provide information on FASD to families and improve communication between families and professionals. In addition, the aim is to highlight the benefits that a child with FASD can experience when the family and the proper team of professionals

are involved in the support of that child. The individualized support required by individuals with FASD will be positively impacted by this manual and the information focussed on improving communication between families and professionals involved in the support of a child with FASD.

Chapter 4: Parental Guide to FASD

Introduction and Purpose

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that encompasses the many disorders and conditions caused by a fetus being exposed to alcohol in utero. Prenatal alcohol exposure accounts for a large number of the population of individuals with development and cognitive disabilities, and is the number one preventable developmental disability. FASD is a very serious condition that has many different, severe, and individualised presenting symptoms. This disorder has no cure and there is no universally established intervention method. It has been suggested that the diverse and individualised presenting symptoms requires the involvement of many professionals. Often it can be difficult to coordinate support involving many professionals; however, it is important that the multidisciplinary team supporting a child with FASD work together to provide effective, consistent, and unified support to the child. Many professionals suggest that families should be at the helm of this support as family support has been shown to have a large positive effect on the life of a child with FASD. The support that can be provided by a family is a type of support that cannot be duplicated non-familial supports, and families should be aware of the enormous impact that they can have on children with FASD and their future.

The purpose of this manual is to provide families with information that may assist them in understanding FASD and being better equipped to communicate with other professionals. It is important that all team members of a multidisciplinary team are aware of their role and ensure that they competently fill that role, and this includes families. Part of the role of family members is to be informed on their child's presenting concerns and

access the appropriate supports that their child may need. This is not always an easy task and it does require a significant amount of time and energy. Families are the closest support to a child and the information that they can provide to professionals about a child with FASD can be critical for effective support. Often families and professionals overlook the importance of family involvement and incorporating the information that families possess into the support of a child with FASD. The intent is that the information in this manual will inform families on a process of better supporting children with FASD towards early diagnosis, developing social connections, managing cognitive and behavioural impairments, and ultimately living their best life possible. This manual is not an all encompassing guide to supporting children with FASD; however, it does provide an easy to read guide on gaining a better understanding of FASD and useful information to aid in the support of children with FASD.

An important note is the use of the word family in this manual will replace various family structures. There are many different family make-ups; however, for the sake of simplicity the word family and parents will be used throughout this manual and these words will be synonymous with foster parents, adoptive parents, guardians, and primary caregivers.

History of FASD

The physical abnormalities associated with FASD as they relate to confirmed cases of mothers who chronically consumed alcohol through their pregnancy was discovered by Kenneth Jones, David Smith, Christy Ulleland, and Ann Streissguth. Their clinical findings revealed eight cases of children who displayed similar patterns of altered facial features and functioning that were the result of prenatal alcohol exposure. Kenneth

Jones and David Smith later reported on evidence that suggest that the negative impact of prenatal alcohol exposure is not a new discovery and that there was additional evidence to confirm its effects. They termed the disorder “fetal alcohol syndrome” and the identification of the disorder was based on common patterns of facial abnormalities, growth deficiency, and abnormal limb development. Since this discovery FAS has been extensively studied and a substantial amount of knowledge surrounding this topic has been uncovered.

Prevalence of FASD

The actual number of people who are affected by FASD is a difficult number to determine and most available numbers are more of an approximation. The issue with assessing the prevalence of FASD comes from the wide range of symptoms that exist, the need for an interdisciplinary assessment and diagnosis, and not all cases of FASD are reported or diagnosed. The prevalence of FAS maybe more accurate as the symptoms are more recognizable and the diagnosis is fairly straightforward. Paul Sampson and colleagues reported that the number of people in the United States impacted by FAS was estimated to be between three and four people for every thousand births. Albert Chudley and his colleagues found similar number for FAS and found that the prevalence of FASD was approximately nine people per thousand births. Although no national statistic was found for Canada, it was noted that similar rates of FAS and FASD were established in various regions throughout the country. These numbers would suggest that FASD is a very serious problem and hopefully by increasing others awareness of this growing concern the rate of children impacted will decrease. It has been suggested that FASD is a

condition that is occurring throughout the world and that it is the leading cause of preventable birth defects and developmental disabilities.

Role of the Family in Supporting a Child with FASD

One critical component of effective support for children with FASD is the families and the role the family plays in reducing the risks associated with prenatal alcohol exposure. The family make-up can vary depending on the situation, but for the purpose of this paper the terms parents and families will be used and these terms will be the substitute for primary care-giver, adoptive parents/families, and foster parents/families. It has been suggested that approximately 80% of children with FASD do not live with their biological parents. The impact of the family can positively or negatively influence a child with FASD depending on whether or not the family environment is stable and nurturing. Ann Streissguth suggests that a poor family environment could be a factor in various adaptive behaviour issues; however, a stable and supportive home has been associated with positive life outcomes. She points out that the best opportunity for a child with FASD is to have a positive and supportive family life coupled with an early diagnosis. The necessity of an early diagnosis allows for the family to gain an understanding of the child's disorder early and be better able to access the necessary supports. For a child with FASD a nurturing home and early diagnosis can lead to more effective transitions to adolescents and adulthood, as well as create closer relationships within a family.

There are critical family characteristics that a family should possess in order to properly support a child with FASD. First, a family should be the communication link to professionals, and fully inform professionals on their child and the child's support needs.

Second, families would benefit from becoming involved in support groups and not only share information, but also gather information from other families who are raising children with similar concerns. Finally, families need to play the role of the advocate and speak for their children and be directly involved in their child's treatment. It has been shown that families that are involved in the support of a child with FASD produce more positive outcomes for the child. This type of approach is known as a family-centered approach and it is a critical element in the support of children with FASD. Often the issue for parents and families is receiving the proper education and knowing how to effectively communicate with professionals. As mentioned above, the intent of this parental guide is to assist in bridging the gap between good family intentions and the effective support of children with FASD. The following are important topics that relate to families working towards supporting a child with FASD.

Accepting a child with a disability. It can be a very difficult time for parents when they discover that their child has a disability. Often when parents are not provided with enough information, and they are dealing with professionals who have limited information to give, they are left feeling lonely, isolated, and have difficulties coping. Teresa Whitehurst identified six common themes parents of children with disabilities go through when they first discover that something is different with their child. The six common themes identified were first becoming aware that something is wrong, experiencing the disorder as a challenge, experiencing differences in their child, experiencing emotional conflict, experiencing disability, and experiencing support. It is important for parents and families to allow themselves time to go through the process of accepting that their child is different from most children. In addition, families need to

make the decision to educate themselves on their child's disability and get properly positioned to provide their child with the necessary supports. Ann Streissguth suggests that parents of children with FASD who have a limited understanding of the disorder, lack access to appropriate resources, and who have poor coping skills leave their children at a greater risk of developing secondary disabilities.

Importance of early diagnosis. The importance of an early diagnosis is mentioned throughout this manual, but the importance of this topic requires its own section. A diagnosis of FASD is the treatment starting point for a child with FASD and it is often the component of support that provides a direction for all parties involved. An appropriate diagnosis allows for parents to gain a better understanding the issues their child is facing and it provides professionals with a foundation to work off of. An early diagnosis allows for more time to put the appropriate supports in place, gives the family a better chance to prepare and get educated, and provides family and professionals a greater opportunity to meet each other communication needs. Many professionals in the field of FASD have pointed out that early diagnosis has been associated with better outcomes for children with FASD.

Secondary disabilities. It is important to understand the difference between primary and secondary disabilities as the way FASD presents in a child is not always directly related to prenatal exposure to alcohol. A primary disability refers to the disability that a child is born with and this encompasses the direct impact of prenatal exposure to alcohol. This would include many of the impairments discussed below such as cognitive (i.e., inattention), social (i.e., lack of response to social cues), behavioural (i.e., poor moral judgment), and physical symptoms (i.e., facial abnormalities). A

secondary disability refers to disabilities that occur after birth and are usually due to a mismatch between life skills/functioning and the individual's environment. In regards to FASD, it is common to see the development of secondary disabilities such as disruption in a school environment, trouble with the law, inappropriate sexual behaviour, mental health concerns, and drug and alcohol related problems. It has been suggested that secondary disability concerns can be exacerbated by things such as later life diagnosis, lack of services, lack of intervention strategies, and/or poor intervention strategies. Although many resources are not available to all families and individuals it is helpful to be aware of secondary disabilities and to work towards an effective treatment plan as early as possible.

Access to resources and limitations. There are many resources that are available to families and individuals; however access to these resources can be limited. For families specifically there are limitations related to socioeconomic status, geographic location, and access to technology (i.e., internet). Although the government in countries such Canada put a large amount of money towards the support of children with FASD there is still a cost to families who are supporting a child with FASD. Often this money is not always available due to income restraints and this makes effective support more difficult, but not impossible. There are limitations related to where a person lives and what community and/or school supports have been established for children with FASD. This is an unfortunate reality for some families; however, it is important for families to access as many resources that are available and be creative in the support that is offered to their children. Various useful resources are listed in the final section of this manual and

these resources could be helpful to families who do not live close to professionals who specialize in the support of children with FASD.

Common Misconceptions of Individuals with FASD

As is the case with many disorders or labels there is a stigma that is attached to FASD and that stigma is perpetuated by many misconceptions. It is detrimental to the support of individuals with FASD to be surrounded by misinformation as it creates more barriers that the individual has to climb over. The intent of this section is to inform families on these misconceptions which will hopefully lead to more informed decision making regarding their children. Furthermore, by exposing the following misconceptions it should lead to more people being informed about FASD, and assist in detaching negative stigma from this disorder.

All individuals with FASD have below average intelligence. It is well documented that prenatal exposure to alcohol can result in brain damage and this damage can lead to reduced cognitive functioning and/or intelligence. Below average intelligence has become known as a given with individuals with FASD, but this is not always the case. There are two issues with assuming that all individuals with FASD have below average intelligence. First, there are many factors that contribute to the severity of brain damage that an individual may experience due to prenatal alcohol exposure. These many factors lead to a very diverse set of presenting symptoms which makes it difficult, if not impossible, to attach a blanket statement to individuals with FASD. Second, Ann Striessguth and colleagues have shown that even individuals with full FAS have been found to have intelligence scores within the average range. This is not to say that prenatal

alcohol exposure does not have an impact on intelligence, but it is not accurate to suggest that all individuals with FASD have below average intelligence.

Behaviour problems associated with FASD is the result of poor parenting.

Parenting and environment play an integral role in a child's development; however, the development of a child does not solely rest on the parents and this is true for children with FASD as well. A child with FASD who is raised in a supportive home may still experience behavioural, cognitive, and social skills difficulties. As mentioned above, prenatal exposure to alcohol is associated with brain damage and the symptoms resulting from certain damaged areas may have a lifelong impact on the effected individual and may override environmental influences. Although it is important to note that a supportive family life has been associated with more positive outcomes for children with FASD.

Society gives up on individual who have been labelled "FASD". There are significant barriers that individuals with FASD and their families have to overcome, and financial support is one of those barriers. Brenda Strade and colleagues highlighted the significant amount of support that the Canadian government provides to individuals with FASD. Specifically, it was estimated that Canada pays approximately \$5.3 billion per year towards the support of individuals between the ages of zero and 53 who have been diagnosed with FASD. This suggests that societal support is going to those who have been identified as having FASD and that the label in this sense should not be a deterrent. It is an expensive endeavour to fund the support of children with FASD and early diagnosis and acceptance could lead to greater access to resources.

Children with FASD eventually outgrow the disorder. It would be nice if FASD was something that a child could outgrow, but it is simply just not the case.

Symptoms may change over time as individuals find effective ways to manage or adapt to symptoms; however, many symptoms of brain damage and secondary disabilities persist into adulthood. Ann Striessguth and colleagues identified a high percentage of individuals with FASD who experience lifelong disruption in a school environment, trouble with the law, inappropriate sexual behaviour, and drug and alcohol related problems. In addition, adults with FASD are at a greater risk for developing mental illnesses such as depression and anxiety related disorders. It is important to note that symptoms that persist into adulthood are exacerbated by a poor upbringing and late diagnosis.

The negative impact of the diagnosis can be detrimental to a child's development. Experts in the field of FASD such as Ann Streissguth have highlighted the importance of a diagnosis and especially an early diagnosis. Early diagnosis allows individuals and families greater access to appropriate interventions, financial resources, and community supports. Early access to resources can play a key role in children with FASD receiving the supports they need to live the best life possible. It has been suggested that early diagnosis and increased access to resources drastically reduces the impact, and possibly the development of, secondary disabilities such as unemployment, disrupted school experience, mental health problems, trouble with the law, and inappropriate sexual behaviour. Furthermore, children with FASD require a team of professionals to support them as their needs are often diverse and many. An early diagnosis provides a better opportunity for an effective team of professionals to be put in place, and for communication between individuals with FASD, families, and professionals to start early.

There are no clear treatment options for individuals with FASD. It is true that there is no cure for FASD, but there are many effective treatment options that can assist a child with FASD. A child with FASD can experience many struggles and there are strategies available for assisting with those struggles and in making daily living more manageable and productive. These strategies and interventions include psycho-educational, psychosocial, psychopharmacological, and neuropsychological profiling (these strategies are discussed in the interventions section). In addition, early diagnosis and a supportive upbringing have been shown to have a positive impact on children with FASD. This suggests that although there is no clear treatment path for children with FASD there are options that can assist in achieving better outcomes for children with FASD.

Understanding the Diagnostic Terms of FASD

A mother who ingests alcohol while pregnant puts the developing fetus at risk of subsequently developing FASD. Alcohol is a teratogen meaning that when consumed prenatally alcohol can negatively impact the fetus. The impact of prenatal alcohol exposure can potentially have a severe and lifelong impact on the child. The impact may include facial dysmorphism, growth deficiency, brain structure abnormalities, cognitive delays, behavioural issues, and social difficulties. It is important to note that prenatal exposure to alcohol does not directly lead to all of the complications listed, and exposed individuals often experience a combination of the various negative symptoms. The spectrum of these symptoms is known as FASD and the diagnoses associated to specific conditions such as Fetal Alcohol Syndrome (FAS) are housed under the term FASD. The purpose of highlighting these terms is to help better inform families and individuals who

are dealing with the difficulties of prenatal exposure to alcohol, but also to aid in more informed conversation with professionals involved in the support of a child with FASD. The term FASD is used throughout this manual as a representation of all conditions caused by prenatal exposure to alcohol. There are instances when the information presented pertains to a specific condition (i.e., FAS) and in those cases the relevant term (FAS) will be used.

What are the differences between FAS and FASD? The acronym FAS (fetal alcohol syndrome) is often used interchangeably with FASD (fetal alcohol spectrum disorder), but the terms are not exactly the same. FASD is a blanket or umbrella term that refers to the wide range of conditions that can result for prenatal exposure to alcohol. The Institute of Medicine (IOM) has developed diagnostic categories to represent the many different conditions and symptoms that can present from a fetus being prenatally exposed to alcohol. FAS is one condition that is under the umbrella term of FASD and this condition is one of the most recognizable and severe condition on the FASD spectrum of conditions. In order for FAS to be diagnosed the individual needs to display the facial abnormalities associated with this condition, growth deficiency, and abnormalities in brain. Often a diagnosis is made with confirmation of maternal consumption of alcohol, but in some cases it can be made without.

What are the abnormal facial features associated with FAS? The abnormal facial features associated with FAS are known as facial dysmorphism and can be characterized by three distinct facial features that are not typical of a normal child development. Susan Astley and Sterling Clarren describe three main facial features of FAS to be palpebral fissure length, philtrum furrow, and a thinner upper lip. Palpebral

fissure length refers to the distance between the inner corner of the eye and the outer corner of the eye; children with FAS have a shorter palpebral fissure length than children without FAS. Philtrum furrow refers to the vertical groove between the upper lip and the nose; children with FAS do not have a groove and the area between the upper lip and nose is generally smooth. A thinner upper lip is fairly self-explanatory; children with FAS have a very thin upper lip that is noticeable as there is limited exposure of the red portion of the upper lip. The three main facial features of FAS are important information to be aware of, because it may assist in early identification of FAS in a child.

What are the growth deficiencies and brain abnormalities associated with FAS? It is often noted that the common facial features of FAS are the most identifiable characteristic of FASD, and although growth deficiencies and brain abnormalities are less noticeable they can have a large impact on the individual. As Robert Sokol and Sterling Clarren have pointed out, a growth deficiency refers to the height and length measurements of prenatal and postnatal growth that are in the tenth percentile. This means that children with FAS would be much smaller than the average normal developing child. It is important to note that growth deficiency is a symptom of FAS, but having a child with a growth deficiency does not necessarily suggest that the child has FAS. This is also true for the brain abnormalities found in children with FAS. Sarah Mattson and her colleagues found that individuals with FAS had a smaller than normal head size and an overall reduction in the size of the brain. The reduction in the size of various brain structures has been associated with many of the cognitive and behavioural issues displayed by children with FAS.

Other conditions caused by prenatal alcohol exposure. The following information was originally put together by Eugene Hoyme and is based on the diagnostic criteria outlined by the Institute of Medicine.

- **Partial Fetal Alcohol Syndrome (pFAS).** As the name suggests, pFAS is very similar to FAS. The diagnostic requirements of this disorder include the presence of all three physical features (facial features, growth deficiency, brain abnormalities), but does not require the presence of all three facial features.
- **Alcohol-Related Birth Defects (ARBD).** The diagnosis of ARBD is characterised by a child that displays normal growth development and intelligence, but has some brain structure abnormalities.
- **Alcohol-Related Neurodevelopment Disorder (ARND).** The diagnosis of ARND involves the confirmation of maternal alcohol consumption and is characterized by a child that display normal growth and structural development, but who has cognitive and behavioural issues typical of children prenatally exposed to alcohol. It is important that these behaviours are best accounted for by prenatal exposure to alcohol and not better explained by a similarity to family members who have not been prenatally exposed to alcohol.
- **Fetal Alcohol Effects (FAE).** FAE is similar to ARND in that the child develops normally, but displays severe cognitive and behavioural symptoms that are definitively linked to significant prenatal exposure to alcohol.

Cognitive, Behavioural, and Social Abnormalities

As discussed above, there are many physical abnormalities that can result from prenatally exposing a child to alcohol. One area that is impacted is the brain and how the brain develops in a child with FASD. A child with FASD can experience a wide range of cognitive and behavioural symptoms that may be in part be the result of abnormal brain development. The reason for not splitting the following two sections into cognitive symptoms and behavioural symptoms is that the themes that seemed to emerge from the many symptoms that occurred fell more into social and adaptive function, and executive functioning. Children with FASD often experience severe deficits in social functioning and in the way that they process information. It is important to recognize these deficits in order to ensure that support is centered on the actually issue the child is experiencing.

Social and adaptive functioning. Socialization is a critical component to lives of many, and to have inherent issues in the area of socialization can be detrimental to a child's development. Shannon Whaley and colleagues found that children with FASD displayed much lower functioning in the area of socialization when compared to same aged children without FASD. As we live in a social world this would suggest that children with FASD are at a disadvantage when it comes to building relationships and adapting to social situations. However, social skills are something that can be taught and social skills training has been shown to be effective in assisting children with FASD with increasing their social and adaptive functioning. This is a process that can require families and professionals working together and is often more effective when the process is started at a young age.

Social cognition. Although it has been shown that children with FASD have difficulties in the area of socialization it is often helpful to identify what specific difficulties can occur. Christine McGee and colleagues sought to identify the social difficulties that children with FASD can experience. What resulted from this investigation was that children with FASD struggle with identifying and implementing appropriate responses to social situations. Specifically, children with FASD often attend to irrelevant information, describe competent responses to be ineffective and tend to favour less competent responses, generate aggressive responses, provide few pro-social goals, and often did not use tone of voice and eye contact effectively. This suggests that children with FASD experience difficulties with processing incoming social information and applying appropriate social responses.

Moral development. Children with FASD have been shown to have concerns with moral development. This is not to say that children with FASD are “immoral people”, but concerns with processing social cues may lead to concerns with making morally appropriate decisions. Kelly Nash and colleagues found that when children with FASD were compared to children with Attention Deficit Hyperactivity Disorder (ADHD) and children with no diagnosed condition, the children with FASD were shown to have a greater propensity for lying, cheating, and displaying a lack of guilt. However, children with ADHD were also shown to have concerns with lying and cheating. Carmen Rasmussen and colleagues showed a similar result, and also found that children with FASD are better at concealing a lie than other children. Children with FASD do not only display less guilt, but they are less likely to reveal a transgression if questioned. It can be speculated whether or not children possess the ability to monitor certain moral

behaviours, but it is important to note that a concern with moral development exist and support in this area may need to be provided.

Executive functioning. Executive functioning is the conscious control of higher order psychological functioning that involves goal oriented behaviour. Higher order psychological processes involve mental processes such as planning, organized searches, inhibitions, memory storage, and the fluency of processing information. In terms of assessing executive functioning capabilities this could mean presenting individuals with a problem and gaining a better understanding of how they utilize higher order mental processes. Courtney Green and colleagues found that children with FASD experience struggles related to spatial working memory and mentally recording information about their environment and surroundings. Children with FASD were also found to have slow reaction times, longer reaction times, and more all-around issues with problem solving when compared to same aged children without FASD. Some researchers have suggested that these issues with executive function could be linked to the structural abnormalities in the brain, but no conclusive evidence was found.

Learning and memory. It is commonly suggested that children with FASD display deficits in learning and memory capabilities. Learning and memory is based on the ability to store incoming information in the brain and being able to build on that information with new incoming information. Children with FASD have been shown to have difficulties with properly processing and storing incoming information. Specifically, they can experience struggles with verbal learning involving writing and speaking. For example, a child with FASD may have difficulties picking up an implied meaning of incoming information. This is not to suggest that children with FASD cannot learn or

remember things, but they do experience areas of difficulties and these areas should be recognized and supported if necessary.

Concept formation. Another difficulty that children with FASD may experience is mentally categorizing information to form concepts. The ability to put information together in categories is the basis for abstract thought and problem solving which is major part of everyday life. Christine McGee and colleagues conducted a study which involved running children with FASD and children without FASD through a series of test such as the Wisconsin Card Sorting Test (WCST) in order to gain a better understanding of each child's ability to form concepts. They found that children with FASD when compared to children without FASD had difficulties verbalizing concepts, made more errors, provided more *perseverative responses* (continually repeating a response even in the absence of being prompted), and displayed poorer responses to feedback. This suggests that children with FASD may experience difficulty with putting ideas together to complete a task even when they are given clear instructions. As mentioned above, forming concepts is a major part of everyday life which means that children who struggle with forming concepts may consequently experience struggles in many areas of their life.

Concept formation and social problem solving. Children with FASD have been shown to have difficulties forming concepts and this can translate to social settings and experiencing difficulties in social problem solving. Christine McGee and colleagues performed a study (a different study than the aforementioned study) that involved questioning parents with children with FASD and children without FASD on their child's ability to handle socially difficult situations. They discovered that children with FASD presented poor social problem solving skills, and were more likely to produce pessimistic

responses as well as being more likely to become frustrated when compared to same aged children without FASD. The parent reports revealed that children with FASD have more issues with controlling behaviour and emotions, shifting between tasks, and organizing and planning tasks. Both studies conducted by McGee and colleagues revealed that children with FASD experience struggles with putting the necessary information together in order to effectively solve problems.

Inattention. Children who have been prenatally exposed to alcohol are well known for having issues with attention and this apparent deficit in attention has been the focus of many research studies. One study in particular which was conducted by Sarah Mattson sought to identify specific areas of attention deficit that children with FASD struggle in. Their study focused on visual focus, auditory focus, and then children's ability to switch their focus between auditory and visual focus. When the children with FASD were compared to children without FASD it was shown that children with FASD struggle more with visual focus and switching between both auditory and visual focus, and slower on all time intervals. However, children with FASD were comparable to children without expect on longer time intervals. In addition, children with FASD were shown to display similar accuracy on performing task and only differed from the control group in ability to maintain focus on the stimuli. This suggest that children with FASD may experience difficulty focussing their attention for long periods of time (especially with visual stimuli), and maintaining their focus when switching from one task to another.

Comorbid Conditions Associated with FASD

Comorbid disorders refer to other disorders that an individual can have in addition to a main diagnosed condition. In terms of FASD, there are many conditions that commonly co-occur with the diagnosis of FASD and those conditions are important to highlight and discuss due to the possible complicating nature of conflicting symptoms and presentation. It may be the case that some symptoms are better explained by another diagnosable conditions and it is important for professionals and families to explore possible co-occurring disorders in order to best describe what a specific child is dealing with. This section is meant to highlight disorders that commonly co-occur with FASD.

FASD and ADHD. It has been suggested that prenatally exposing a child to alcohol increase the chance of that child developing Attention Deficit Hyperactivity Disorder by two and half times. There has been some debate on whether ADHD is a commonly co-occurring disorder or whether the ADHD is being diagnosed based on the attention difficulties experienced by children with FASD (as mentioned in the last section). In one study Libbe Kooistra and colleagues compared the performance of children with FASD, children with ADHD, and children with neither on a series of tasks involving attention. They found that children with FASD and ADHD did experience similar attention difficulties when compared to children with neither diagnosis. Where the FASD and ADHD groups differed is when the task involved transitioning between a slow event rate and a fast event rate. Children with ADHD appeared to struggle more with being under-stimulated whereas children with FASD struggled with being over-stimulated. This finding could be a key in identifying differences in diagnosis, and could lead to a better understanding of children who have FASD with a co-occurring diagnosis

of ADHD. However, how the two conditions present could be quite different depending on the individual.

Other comorbid conditions. There are many other disorders and accompanying symptoms that could co-occur with FASD and complicate the understanding of presenting symptoms. In one study it was found that of a group of children prenatally exposed to alcohol approximately 35% met the diagnostic criteria for bipolar disorder and 26% met the criteria for major depressive disorder or adjustment disorder with depressed mood. Other studies have shown that prenatal alcohol exposure has been associated with diagnoses of anxiety disorders, epilepsy and seizure disorders, and alcohol abuse related disorders. The actual prevalence rates of each of these co-occurring disorders differ depending on the specific diagnoses. However, being aware of the possibility and likelihood of co-morbid disorders is a critical component to providing proper support, and putting together effective and individualized treatment plans.

Interventions Utilized in the Support of Children with FASD

As mentioned above, early diagnosis provides a child with FASD a better chance for positive outcomes. One of the benefits of early diagnosis is it allows for treatment plans to be implemented early, and for families and professionals more time to assess treatment outcomes. The need for outcome assessment comes from the diverse nature of FASD and that there is no one treatment that has been found to be effective. There are many different treatment options available and part of the concern with FASD is finding a treatment direction that works. Some of the treatments include psycho-educational, psychosocial, psychopharmacological, and a possible combinations. In addition, neuropsychological profiling has been suggested as a worthwhile process to explore with

children who have been prenatally exposed to alcohol. The following will be an explanation of the basics of each treatment option and should not be looked at as resources for specific treatment methods.

Psycho-educational. Psycho-educational strategies are focussed the psychological concerns experienced by children with FASD and implementing individualized educational methods to meet a specific child's needs. This type of method has been shown to be effective for children with FASD who are in an educational setting. One element to this method that can be critical is ensuring that both parent and educators are knowledgeable on the specific program being implemented. Claire Coles and colleagues designed a study aimed at showing the effectiveness of psycho-education methods in helping children with FASD develop mathematical skills. The study included a workshop for caregivers and teachers focussed on educating the participants on the impact FASD can have on a child. They found that children with FASD who have knowledgeable caregivers and teachers, and who have been put through a six week math program tailored to their individual needs showed significant improvement. Specifically, they found that there was a noticeable reduction in behavioural disturbances, and intellectual capabilities were significantly higher for those children who had individualized learning plans. This suggests that it is not only important to individualize learning plans and educate parents on the psycho-educational process, but it is also worthwhile to educate families and teachers on the impact of FASD.

Psychosocial. Psychosocial interventions focus on the social and the psychological concerns experienced by children who have been prenatally exposed to alcohol. The social aspect of a person's life is an important aspect and previously

mentioned this is a major road block for children with FASD. Mary O'Connor and colleagues sought to show the value in psychosocial interventions by putting together a social training program and providing it to one group of children with FASD and compared that group to another group of children with FASD who were delayed in receiving the training. The training involved providing instruction on social rules through modeling, rehearsal, performance feedback during treatment, rehearsal at home, homework assignments, and coaching by parents during play with peers. A major part of this process involved educating parents on process of social skills training and allowing for more consistency in the approach to the children. They found that when compared to the group that was delayed the children who received the training showed a significant increase in social skills and a reduction in behavioural concerns. This suggests that there is some merit to providing children with FASD social skills training and targeting certain social deficits specifically. However, this once again involves parents taking a role in the treatment and being educated on the process in order to provide consistency.

Psychopharmacological. Medication has become a critical factor in how illness is treated and it is relied on when it comes to treating FASD. However, the results on the effectiveness of medication suggest that medication cannot solely be relied on in the treatment of FASD. Jenna Doig and colleagues conducted a study looking at the effectiveness of psychostimulants in the treatment of children with ADHD comorbid with FASD. It was found that the medication was effective in reducing hyperactivity/impulsivity and opposition/defiance, but in terms of inattention no significant improvements were noted. No studies were found specifically focused on the effectiveness of medication in the treatment of FASD, and this may be due to the

diversity of symptoms and the requirement of various medications. Given the wide range of symptoms associated with FASD it may be more efficacious to only consider medication in conjunction with other treatments such as psychosocial interventions.

Psychosocial and psychopharmacological. As mentioned above, there are many positive benefits that can be gained for implementing psychosocial interventions with children prenatally exposed to alcohol. It seems intuitive that by coupling an already effective treatment method with a medication would yield a positive result. This does appear to be the case, but Fred Frankel and his colleagues found that the positive result may depend on the medication and psychostimulants may not be the best choice for children with FASD. They conducted a study that looked at comparing the effectiveness of antipsychotic medication coupled with Child Friendship Training (CFT) and psychostimulants medication and CFT. It was shown that antipsychotic medication and CFT was the more effective combination. The children with FASD in this group displayed significant improvement in the areas of assertion, self-control, and managing problem behaviour. The authors suggest that these results could be impacted by dosage, but that one combination was more efficacious than the other.

Neuropsychological profiling. It has been suggested throughout this manual the importance of obtaining an early and accurate diagnosis for children impacted by prenatal exposure to alcohol; however, obtaining a diagnosis can be difficult given the diversity of symptoms and the presents of less overt symptoms. Neuropsychological profiling is one method for assessing symptoms of FASD that are not as obvious as symptoms such as facial dysmorphia. The process involves the use of several neurological test batteries aimed at assessing areas such as executive function, attention, spatial learning and

memory, fine motor speed, and visual motor integration. The resulting information can be used to identify areas of dysfunction that are related to common dysfunction associated with FASD as well as highlight areas of concern that require attention and support.

Neurological profiling is not only useful for diagnosis, but can also aid in developing a more informed and comprehensive treatment plan that focuses on the specific needs of an individual child.

Multidisciplinary Support and the Support of Individuals with FASD

It has been suggested by many professionals that diverse presentation of symptoms associated with FASD and the need for individualized support would be best met with a multidisciplinary approach. Children with FASD need the assistance of many different professionals and it would be beneficial for all of these professionals to work together to meet the specific needs of the child. A common group of professionals may include families, community support workers, coordinator for case management, physician specifically trained in FASD diagnosis, psychologist, occupational therapist, and speech-language pathologist, teachers, and school counsellors. It is important to note that some of these professionals are not in the typical realm of support that would be expected for a child. Supports need to reach outside of the family, schools, and doctors offices. Community supports need to be involved in the support group surrounding a child with FASD and these supports may always be with the individuals as they strive towards their independence up into adulthood. There is little research that outlines how this support would be coordinated in terms of supporting FASD; however, information focused on utilizing a multidisciplinary approach to support children with ADHD could be useful.

J.R. Parr and colleagues reviewed almost 400 case notes of children diagnosed with ADHD who receive support. They found that the major hurdle for many professionals trying to work together is communication and that the communication between families, schools and professional was often not happening. This lack of communication can result in important information not being gathered and overlap in support being provided. The overlap in support may even take the form of some professionals performing tasks that they are not qualified to perform. It has been suggested that the best course of action in a multidisciplinary approach is to assign a case manager that will communicate with families, involve necessary professionals, and access appropriate community resources. The case manager would be the communication link between parties involved in an individual child's support and would coordinate necessary meetings between parties. No research was found to show that this method of support would be more effective than more traditional methods of support, but it can be suggested that a case manager would assist in overcoming the communication barrier that often occurs in large teams of support. Ann Striessguth and others point out that by families, physicians, and community supports working together children with FASD have a better chance at reducing negative outcomes and ensuring they are raised in stable, structured, and nurturing environments.

Importance of structure and routine. Another major benefit of stressing communication in a multidisciplinary approach to supporting children with FASD is consistency. Children with FASD respond better when they are supported with a concrete approach rooted in structure, routine, repetition, and consistency. For example, it may be helpful to create a calendar for a child with FASD that outlines specific times for daily

activities. This can be as specific as creating time blocks for homework, friends/family, TV, supper, and a bed time. It is especially important for families and teachers to communicate specific routines as they would be the main supports in a child's life and this communication assists in creating consistency. Good communication practice between families and professionals allows for both parties to more effectively approach individual children in a specific manner. This creates an environment where children with FASD can consistently be immersed in structured routine and approach that will provide them with the best chance for success (a list of professionals is provided in appendix A).

Families Communicating with Professionals

The needs of individuals with developmental disabilities are often very specific to the individuals and has long been suggested that effective support includes the collaboration of families and professionals. As mentioned above, an approach to an effective collaboration is a family-centered approach involving a partnership that is rooted in the family's values and philosophies. For example, there may be culture specific practices that a family wishes to incorporate into a child's support and it is critical that professionals remain mindful of these individual factors. One of the major road blocks that families and professionals face when building a relationship is unsuccessfully creating a collaborative, trusting, value focussed, and empowering relationship. These factors are requirement in a family-professional relationship just like they are necessary components in most, if not all, successful relationships. Both parties need to be able to communicate with each other and allow the other to speak and contribute. It has been suggested that families and professionals do not often know what to expect from each other which makes building a mutual trust and respect very difficult.

Communication necessities for working together. It has been shown that there are many factors to an effective working relationship between families and professionals. Martha Blue-Banning and colleagues discovered from the information they gathered from family and professional focus groups that there are six broad categories of communication necessities. The six categories are: communication, commitment, equality, skills, trust, and respect. It is important that families and professionals have similar goals for the child in question and are working towards a similar outcome. For example, a family may wish to have a medication free treatment plan if possible and it is important for professionals to work with that in mind or refer the family to a professional that operates more in line with what they are looking for. It is also important for both parties to view one another as equals. It can put a strain on a working relationship when professionals portray themselves as being above families, or when families push their opinion on professionals and are disrespectful. Both parties need to be equal in the working relationship and they need to be able to trust each other. Families and professionals also need to trust each other. Families need to trust that their child is safe with professionals and that all interactions are held in confidence, and professionals need to trust that families are committed to their children and the process of support. Families can be a great source of information for professionals and professionals can be an excellent resource for families; therefore it is important that both parties understand one another (a list of communication tips is provided in appendix B).

Understanding each other. Both families and professionals serve a purpose in the support of children with FASD; however understanding each other's purpose can be difficult. Families appreciate professionals who are knowledgeable and skilled in their

practice, and possess the ability to adapt to their child's individual needs. It can also be beneficial to the working relationship if professionals refrain from using jargon and work towards helping the parents/families understand information relevant to their child's support. For professionals, it is helpful if families are open in their communication, respectful in their interactions, and are prepared and on-time for appointments. One helpful strategy for families to use for being prepared is to write down relevant questions and bring those questions to the appointment. It may also be useful to take notes during appointments to ensure that important information is not missed. Often families and professionals can misunderstand each other; however, if both parties are working towards building a relationship that they can rely on it gives the working relationship a better chance of being effective (a preparedness sheet is provided in appendix C).

Families Communicating with Schools

All professionals involved in the support of children with FASD are important; however, a focus is being put on school due to the amount of time that children spend in schools. The involvement of school professionals may include teachers, school administrators, teacher's aids, school counsellors, and school psychologists. It is important for families to establish a good rapport and working relationship with those involved in their child's support given that a child with FASD often has extensive and individualized support needs. The factors of a good working relationship mentioned above apply to school professionals as well; however, families may be working more closely with school professionals and communication between both parties becomes even more important. Schools have the potential of providing significant amount of support for children with FASD and parents need to be aware of what can be offered and what should

be offered. Often this involves parents sitting down with teachers and other professionals and discussing the specific needs of the child in question and establishing a mutually agreed upon direction for support. In certain cases this may require families to advocate for their child to acquire certain supports, and it may even require access to resources outside of the school. Regardless of where supports for the child end up, families should work towards being part of an effective working relationship with schools as early as possible.

Early intervention and Positive Behaviour Support (PBS). One reason for the importance of acquiring a diagnosis for child with FASD is that allows for effective supports to be established early. It is important for children who require specialized supports to have access to useful interventions at a young age. There are many early intervention strategies for children with developmental disabilities, but one worth mentioning for purpose of gaining a better understanding of early interventions is Positive Behaviour Supports (PBS). Edward Carr and colleagues outline the importance of PBS in the lives of children with a developmental disability and incorporating the elements of PBS into a school environment. Positive behaviour supports is focused on assisting a child to develop skills that would increase the likelihood of having a normal and successful academic, work, social, recreational, community, and family life. The support is value driven and involves all relevant parties in a child's life to participate in the planning, implementing, and evaluating of the proposed school supports. Given that PBS is value driven it requires families to be involved and working towards assisting professionals to understand their values and the values of their child. Positive behaviour

supports is not necessarily an intervention tool, but it provides a possible guideline for the specialized support needs of a child with FASD.

Evaluating the effectiveness of parent/school collaboration. It has been shown that families can play a large role in creating positive outcomes for their children. Family involvement in a child's education can produce significantly higher positive result for the child. In fact, family involvement such as reading at home with the child has produce better educational results than when activities are done in the classroom. Studies have looked at the effectiveness of family involvement and have attempted to produce similar positive results by creating family and school collaboration. Often it is not the case that family and school collaboration leads to better outcomes for children, but this has been described as a communication issue. Further research would be needed to mend the communication problem between families and schools and test whether or not family/school collaboration would lead to more positive outcomes for children. It is important for families to be an active participant in collaborating with schools and ensuring that the both parties are working towards similar outcomes and are consistent in their approach to support of a child. This becomes especially important in the support of children with FASD given their often diverse cognitive and behavioural concerns.

Summary

Although there is no treatment for FASD, or a universal process for supporting a child with FASD, there is a significant amount of information known about FASD. It is important that the support group around a child with FASD are informed, dedicated, and communicate effectively with each other. Families have been shown to have a major impact in the support process and can be a great source of information and resources for a

team of professionals around a child with FASD. Families play a crucial role in ensuring early diagnosis, initiating a support network, and advocating for their child. The intent of this manual is to assist families in becoming more knowledgeable and aware of information surrounding FASD, and useful information on involving a team of professionals and effectively communicating with those professionals. The effectiveness of the working relationship of a support team could play a large role in creating more positive outcomes for children with FASD.

Appendix A: Resources

As mentioned above, this manual does not cover all of the information relevant to the support of families and individuals impacted by FASD. There is a significant amount of additional information available to individuals and families. The following is a list of some web-based sources and other resources for parents and individuals to access additional information and support.

FASD Websites

Government of Alberta: Human Services, Children and Youth

<http://www.child.alberta.ca/home/594.cfm>

This webpage provides links to many resources in Alberta as well as information on what the Government of Alberta is doing in support of children with FASD.

Government of Alberta: Education, Individualized Program Planning (IPP)

<http://education.alberta.ca/admin/special/resources/ipp.aspx>

This website provides information on individualized school programs designed for students with special needs. There is a section that focuses on parents and how parents can be involved the process of Individualized Program Planning for their child.

FASlink Fetal Alcohol Disorders Society

<http://www.faslink.org/index.htm>

This website is a Canadian based website that was originally developed as a discussion forum for parents looking for more professional information on FASD. The discussion forum is still active and there are many links to useful information.

Fetal Alcohol Syndrome (FAS) Book Shelf/Resources

<http://www.fasbookshelf.com/>

This website is a great source for finding published books and resources on the topic of FASD. Many of the books that were to be suggested resources in this manual are listed on this website.

FASD Connections: Serving Adolescents and Adults with FASD

<http://www.fasdconnections.ca/>

This website is an excellent source for finding current academic articles focussed on FASD. The purpose of this website is to assist families and individuals in accessing current information that will help them become more educated on FASD and supporting FASD in a caring environment.

Lakeland Center for FASD Online

<http://www.lcfasd.com/>

Lakeland Center for FASD is an organization located in Northern Alberta Canada and they are dedicated to providing accurate and effective information, and support, to those impacted by FASD. They provide many services to families and individuals and are a great source of information on FASD. In addition, there are many resources (i.e., books, websites, videos) listed on the website.

Better Endings New Beginnings: A Voice for the Voiceless – FASD

<http://www.betterendings.org/>

This website was created as a resource for parents and individuals who have been impacted by FASD. There is a great deal of information and tools available on this website and it can be an excellent resource for parents.

FASD Support and Resources in Alberta

<http://fasd.typepad.com/>

This website was created by parents of children with FASD and is geared towards providing more support to parents of children with FASD. There are many links to a wide range of information of resources.

Additional Print Resources

Promising Practices, Promising Futures FASD Conference

This is a two day conference that is held annually in Alberta. The conference is multidisciplinary conference centered on FASD and the impact this disorder has on individuals, families, communities, and society.

Living with FASD: A Guide for Parents

By: Sara Graefe

This is a book that is geared towards informing parents about how to raise children with FASD. It contains a large amount of useful information and strategies that can benefit both the parents and children impacted by FASD.

Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living

By: Society of Special Needs Adoptive Parents (SNAP)

This is a guide for parents, caregivers, and others who work with children with FAS. The guide provides useful and update information on FAS and includes information on getting assessments, obtaining referrals, accessing supports for children, and the impact on families.

Fetal Alcohol Spectrum Disorder: A Guide to Awareness and Understanding

By: FASD Support Network of Saskatchewan Inc.

This is guide created to provide a variety of readers with basic information about FASD as well as resources and tools that individuals impacted by FASD may find useful.

Youth and Fetal Alcohol Spectrum Disorder Transitioning Initiative Toolkit

By: Lakeland Center for FASD

The intent of this toolkit is to assist relatively stable youth with a support network to transition into young adulthood. Although the target audience is youth who are transitioning into young adulthood the information is useful for families of children with FASD.

Appendix B: Suggested Members of a Multidisciplinary Team

List of Possible Professional	
Case Manager	Case manager may be a social worker or community support worker that focuses on coordinating the supports surrounding a child with FASD.
Physician	A physician can be responsible for a diagnosis and medical care needs; however, a diagnosis is usually given by a physician who specializes in FASD.
Psychologist	Psychologist can provide necessary supports through the use of assessment and psychological and behaviour management programs.
Speech and Occupational Therapist	Speech and occupational therapist may be necessary components to a support team as they provide specialized support that may assist a child in more effectively navigate through everyday life.
Community Support Workers	Community support workers can be a source of support in assisting a child to develop everyday life skills and can also provide support to families (i.e., respite).
Teachers	Teachers are a major part of a child's life and they can be an important source of information as well as a necessary component in modified education programs.
School Administrators	School administrators play a role in developing and putting into place specialized education plans and programs that a child with

	FASD may require.
School Counsellors	School counsellors can be an integral support to children with FASD. Specifically, assisting with program development, advocating for services, and helping with the transition to the workforce or post-secondary education.

Appendix C: Quick Communication Tips

Quick Communication Checklist	
Avoid Jargon	Professionals should refrain from using jargon that parents do not understand; however, parents also have a responsibility to inform professionals when they require clarification of a term or concept.
Respect	The working relationship between parents and professionals is like most relationships in that it requires respect from both parties in order to be successful.
Preparedness	Parents need to attend appointments on-time and be prepared for appointments and meetings.
Open Communication	Open communication is important in an effective working relationship. Parents should ensure that they are open and honest with professionals to ensure effective communication as well as to make sure the needs of their child are being met.
Trust	Trust is important. No one person can be everything in a support team; therefore, it is important that families can trust professionals will follow through with their responsibilities and vice versa.
Commitment	Commitment of families and professionals is a major part of a working relationship as well as respect. Families need to know that professionals are committed to their child, and professionals need to know that families are also committed to their child and the support process.

Appendix D: Preparedness Sheet**Sample Preparedness Sheet**

This information on this sheet could be prepared by parents in advance to be better prepared for meetings with various professionals

The concerns/symptoms that my child is experiencing are:

The support needs of my child are:

Special concerns for my child are:

My child's interests are:

The values my child has are:

People to contact for emergencies or questions are:

Chapter 5: Conclusion

The impact of prenatal alcohol exposure has been studied and written about for approximately four decades. There is a large amount of information known about FASD; however, there are still many unknowns about FASD and the impact FASD can have on the individual. Prenatal exposure to alcohol has been shown to cause a variety of physical, cognitive, behavioural, and social impairments. The various combinations of symptoms can be diagnosed as different disorders along the continuum of FASD. This suggests that there are many different ways in which FASD can be experienced and presenting symptoms are individualized and specific to the individual. The number of individuals impacted by FASD is growing with the prevalence rates in North America estimated at three out of 1000 births are impacted by FAS and 9 out of 1000 births are impacted by FASD (Chudley et al., 2005). Chandrasena, Mukherjee and Turk (2009) point out that FASD is the leading cause of preventable birth defects and development disabilities making the topic of effective diagnosis and support of individuals with FASD an important topic to explore.

It has been suggested that early diagnosis can lead to more positive outcomes for a child with FASD, and provides a better opportunity to organize an effective support network around the child (Streissguth et al, 2004). Often these support networks involve the collaboration of families and many professionals. This collaboration is known as a multidisciplinary approach and the professionals that may be involved include caseworkers, community support workers, physicians, psychologists, occupational therapist, speech pathologists, teachers, school counsellors, and school administrators. There are many different areas of functioning that can be impacted by prenatal alcohol

exposure and this requires many different professionals to be involved to address the various concerns. It has been suggested that involving many professionals in a support team can be ineffective due to communication breakdowns; however, effective communication is something that can be addressed (Parr, Ward & Inman, 2003). Parr et al. (2003) suggests that families are important component to a support network and families should be guiding the support in order to ensure good communication and consistent support. However, this can be a difficult task for families and may require families to become more educated on the topic of FASD as well as effectively working with a support network.

Initially it may be difficult for families to cope with the knowledge that their child has a developmental disability that will have a lifelong impact on their child. Most parents go through a pattern of grief that involves the six themes of first becoming aware that something is wrong, experiencing the disorder as a challenge, experiencing differences, experiencing emotional conflict, experiencing disability, and experiencing support (Whitehurst, 2011). Whitehurst (2011) identified, from the parents perspective, that an early understanding and access to support is vital for positive outcomes for the child and the family. It can be beneficial for parents to allow for time to cope and work towards setting up supports early. Parents who have difficult time coping and who have limited access to effective support put the child at risk of developing secondary disabilities (Streissguth, Barr, Kogan & Bookstein, 1996); which may have an impact on the child's quality of life. It is important for parents and families to know their role and take part in supporting their child and become knowledgeable on their child's presenting concerns.

Families play a critical role in the support of children with FASD and reducing the risks caused by prenatal alcohol exposure. Streissguth et al. (2004) suggested that children with FASD who are raised in a stable and nurturing environment are less likely to develop adaptive behaviour issues, and are more likely to have positive life outcomes. This supportive environment requires families to be an active member of a child's support team and to advocate for services and communicate with professionals. Neely-Barnes, Graff, Marcenko and Weber (2008) have shown that children who have a developmental disability are better off when their families are involved than when their families are not involved. A family-centered approach to support is an effective way to support a child with FASD (Bruder, 2000; Olson, Oti & Beck, 2009); however, there are still gaps in developing effective methods for training parents on support procedures and communicating effectively with professionals.

A family-centered approach to support should be rooted in the philosophies and values that the family and the child share (Bruder, 2000). These central themes can be lost when communication breaks down and working relationships are not established. There are many different methods in which families and professionals can communicate; however, there are elements of communication that are required to establish a working relationship. Blue-Banning et al. (2004) found that the communication themes of communication, commitment, equality, skills, trust, and respect are critical in developing a productive working relationship between families and professionals. It is important for families and professionals to be aware of how communication can breakdown. However, the information in the above manual is focussed on families as families should be at the

front of the support network and it is important that families are knowledgeable, prepared, and involved in their child's support.

The intent of this project is to highlight current and relevant information on FASD as well as provide families with information on the importance of involving a many professionals in the support of a child with FASD and the need for a good working relationship. There are many different approaches that can be taken in the support of children with FASD and the information provided is meant to be more of a guide rather than a rule. There was little information found on specific methods of communication and how various methods of communication can impact outcomes for a child with FASD. This project and manual may assist in bringing a focus to the importance of involving a family in the support of children with FASD and working towards helping families to effectively communicate with a wide variety of professionals. A possible future direction may be to gear similar information on communication and the importance of a family-centered approach towards professionals in an effort to generate more positive and effective support for children with FASD. Involving many professionals in the support of one child can create confusion on the direction of support, and it would be helpful if all parties were able to listen and communicate with each other in a way that would allow the support network to move as a whole in the direction that is in the best interest of the child.

References

- Astley, S., & Clarren, S. (1995). A fetal alcohol syndrome screening tool. *Alcoholism: Clinical and Experimental Research, 19*, 1565-1571.
- Astley, S., & Clarren, S. (2001). Measuring the facial phenotypes of individuals with prenatal alcohol exposure: Correlations with brain dysfunction. *Alcohol & Alcoholism, 36*, 147-159.
- Baer, J., Sampson, P., Barr, H., Connor, P., & Streissguth, A. (2003). A 21-year longitudinal analysis of the effects of prenatal alcohol exposure on young adult drinking. *Archives of General Psychiatry, 60*, 377-385.
- Bailey, D. (2007). Introduction: Family adaptation to intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 291-292. doi: 10.1002/mrdd.20168
- Bell, S., Stade, B., Reynolds, J., Rassmussen, C., Andrew, G., Hwang, P.,... Carlen, P. (2010). The remarkably high prevalence of epilepsy and seizure history in fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research, 34*, 1084-1089. doi: 10.1111/j.1530-0277.2010.01184.x
- Bhavnagri, N., & Parke, R. (1991). Parents as direct facilitators of children's peer relationships: Effects of age of child and sex of parent. *Journal of Social and Personal Relationships, 8*, 423-440. doi: 10.1177/0265407591083007
- Blue-Banning, M., Summers, J., Frankland, C., Nelson, L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Council for Exceptional Children, 70*, 167-184.

- Bruder, B. (2000). Family-centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education, 20*, 105-115.
- Burd, L., & Christensen, B. (2009). Treatment of fetal alcohol spectrum disorders: Are we ready yet? *Journal of Clinical Psychopharmacology, 29*, 1-4. doi: 10.1097/JCP.0b013e318192eae
- Carr, E., Dunlap, G., Horner, R., Koegel, R., Turnbull, A., Sailor, W.,... Doolabh, A. (2002). Positive behaviour support: Evolution of an applied science. *Journal of Positive Behavior Interventions, 4*, 4-17.
- Chandrasena, A., Mukherjee, R., & Turk, J. (2009). Fetal alcohol spectrum disorders: An overview of interventions for affected individuals. *Child and Adolescent Mental Health, 14*, 162-167. doi:10.1111/j.1475-3588.2008.00504.x
- Chudley, A., Conry, J., Cook, J., Looock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172*, S1-S21. doi: 10.1503/cmaj.1040302
- Chudley, A., Kilgour, A., Cranston, M., & Edwards, M. (2007). Challenges of diagnosis in fetal alcohol syndrome and fetal alcohol spectrum disorder in the adult. *American Journal of Medical Genetics Part C (Seminars in Medical Genetics), 145C*, 261-272. doi: 10.1002/ajmg.c.30140
- Coles, C., Kable, J., & Taddeo, E. (2009). Math performance and behaviour problems in children affected by prenatal alcohol exposure: Intervention and follow-up. *Journal of Developmental & Behavioural Pediatrics, 30*, 7-15.

- Doig, J., McLennan, J., Gibbard, W. (2008). Medication effects on symptoms of attention-deficit/hyperactivity disorder in children with fetal alcohol spectrum disorder. *Journal of Child and Adolescents Psychopharmacology*, *18*, 365-371.
- Fanruzzo, J., McWayne, C., Perry M., & Childs, S. (2004). Multiple dimensions of family involvement and their relations to behavioural and learning competencies for urban, low-income children. *School Psychology Review*, *33*, 467-480.
- Frankel, F., Paley, B., Marquardt, R., & O'Connor, M. (2006). Stimulants, neuroleptics, and Children's Friendship Training for children with fetal alcohol spectrum disorders. *Journal of Child and Adolescents Psychopharmacology*, *16*, 777-789.
- Graefe, S. (2003). *Living with FASD: A guide for parents*. Vancouver: Ben Simon Press.
- Green, J. (2007). Fetal alcohol spectrum disorders: Understanding the effects of prenatal alcohol exposure and supporting students. *Journal of School Health*, *77*, 103-108. doi: 10.1111/j.1746-1561.2007.00178.x
- Green, C., Mihic, A., Nikkel, S., Stade, B., Rasmussen, C., Munoz, D.,...Reynolds, J. (2009). Executive function deficits in children with fetal alcohol spectrum disorders (FASD) measured using the Cambridge Neuropsychological Tests Automated Battery (CANTAB). *The Journal of Child Psychology and Psychiatry*, *50*, 688-697. doi: 10.1111/j.1469-7610.2008.01990.x
- Harry, B., Rueda, R., & Kalyanpur, M. (1999). Cultural reciprocity in sociocultural perspective: Adapting the normalization principle to family collaboration. *Exceptional Children*, *66*, 123-136.

- Hazelwood, E., Bovingdon, T., & Tiemens, K. (2002). The meaning of a multimodal approach for children with ADHD: Experiences of service professionals. *Child: Care, Health & Development*, 28, 301-307.
- Hellemans, K., Sliwowska, J., Verma, P., & Weinberg, J. (2010). Prenatal alcohol exposure: Fetal programming and later life vulnerability to stress, depression and anxiety disorders. *Neuroscience and Biobehavioral Reviews*, 34, 791-807. doi: 10.1016/j.neubiorev.2009.06.004
- Hoyme, E., May, P., Kalberg, W., Kodituwakku, P., Gossage, P., Trujillo, P.,...Robinson, L. (2005). A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 Institute of Medicine Criteria. *Pediatrics*, 115, 39-47. Doi: 10.1542/peds.2004-0259
- Jones, K., & Smith, D. (1973). Recognition of the fetal alcohol syndrome in early infancy. *The Lancet*, 302, 99-1001.
- Jones, K., Smith, D., Ulleland, C., & Streissguth. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *The Lancet*, 301, 1267-1271.
- Kodituwakku, P., Kalberg, W., & May, P. (2001). The effects of prenatal alcohol exposure on executive functioning. *Alcohol Research and Health*, 25, 192-198.
- Kooistra, L., Crawford, S., Gibbard, B., Rampage, B., & Kaplan, B. (2010). Differentiating attention deficits in children with fetal alcohol spectrum disorder or attention-deficit-hyperactivity disorder. *Developmental Medicine & Child Neurology*, 52, 205-211. doi: 10.1111/j.1469-8749.2009.03352.x

- Mattson, S., Calarco, K., & Lang, A. (2006). Focused and shifting attention in children with heavy prenatal alcohol exposure. *Neuropsychology, 20*, 361-369. doi: 10.1037/0894-4105.20.3.361
- Mattson, S., Foroud, T., Sowell, E., Jones, K., Coles, C., Fagerlund, A.,...Riley, E. (2010a). Collaborative initiative on fetal alcohol spectrum disorders: methodology of clinical projects. *Alcohol, 44*, 635-641. doi: 10.1016/j.alcohol.2009.08.005
- Mattson, S., Riley, E., Sowell, E., Jernigan, T., Sobel, D., & Jones, K. (2006). A decrease in the size of basal ganglia in children with fetal alcohol syndrome. *Alcoholism: Clinical and Experimental Research, 20*, 1068-1093. doi: 10.1111/j.1530-0277.1996.tb01951.x
- Mattson, S., Roesch, S., Fagerlund, A., Autti-Ramo, I., Jones, K., May, P.,...Riley, E. (2010b). Toward a neurobehavioural profile of fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research, 34*, 1640-1650. doi: 10.1111/j.1530-0277.2010.01250.x
- May, P., Gossage, P., Kalberg, W., Robinson, L., Buckley, D., Manning, M.,...Hoyme, E. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews, 15*, 176-192. doi: 10.1002/ddrr.68
- McGee, C., Bjorkquist, O., Price, J., Mattson, S., & Riley, E. (2009). Social information processing skills in children with histories of heavy prenatal alcohol exposure. *Journal of Abnormal Child Psychology, 37*, 817-830. doi: 10.1007/s10802-009-9313-5

- McGee, C., Fryer, S., Bjorkquist, O., Mattson, & Riley, E. (2008). Deficits in social problem solving in adolescents with prenatal exposure to alcohol. *The American Journal of Drug and Alcohol Abuse*, *34*, 423-431. doi: 10.1080/00952990802122630
- McGee, C., Schonfeld, A., Roebuck-Spencer, T., Riley, E., & Mattson, S. (2008). Children with heavy prenatal alcohol exposure demonstrate deficits on multiple measures of concept formation. *Alcoholism: Clinical and Experimental Research*, *29*, 1388-1397. doi: 10.1111/j.1530-0277.2008.00707.x
- Mick, E., Briederman, J., Faraone, S., Sayer J., & Kleinman, S. (2002). Case-control study of attention-deficit hyperactivity disorder and maternal smoking, alcohol use, and drug use during pregnancy. *Journal of the American Academy of Child and Adolescent Psychiatry*, *41*, 378-385. doi: 10.1097/00004583-200204000-00009
- Minke, K., & Anderson, K. (2005). Family-school collaboration and positive behaviour support. *Journal of Positive Behavior Interventions*, *7*, 181-185.
- Mutch, R., Peadon, E., Elliot, E., & Bower, C. (2009). Need to establish a national diagnostic capacity for foetal alcohol spectrum disorders. *Journal of Paediatrics and Child Health*, *45*, 79-81. doi: 10.1111/j.1440-1754.2009.01464.x
- Nash, K., Rovet, J., Greenbaum, R., Fantus, E., Nulman, I., & Koren, G. (2006). Identifying the behavioural phenotype in fetal alcohol spectrum disorder: Sensitivity, specificity and screening potential. *Archives of Women's Mental Health*, *9*, 181-186. doi: 10.1007/s00737-006-0130-3

- Neely-Barnes, S., Graff, C., Marcenko, M., & Weber, L. (2008). Family decision making: Benefits to persons with developmental disabilities and their family members. *Intellectual and Developmental Disabilities, 46*, 93-105.
- Niccols, A. (2007). Fetal alcohol syndrome and the developing socio-emotional brain. *Brain and Cognition, 65*, 135-142. doi: 10.1016/j.bandc.2007.02.009
- O'Connor, M., Frankel, F., Paley, B., Schonfeld, A., Carpenter, E., Laugeson, E.,...Marquardt, R. (2006). A controlled social skills training for children with fetal alcohol spectrum disorders. *Journal of Consulting and Clinical Psychology, 74*, 639-648. doi: 10.1037/0022-006X.74.4.639
- Odishaw, J., & Snart, F. (2005). Assessment of cognitive processing in persons with FASD: A promising alternative to traditional IQ measures. *Exceptional Education Canada, 15*, 25-41.
- Olson, H., Oti, R., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews, 15*, 235-249. doi: 10.1002/ddrr.65
- O'Malley, K., Koplun, B., & Dohner, V. (2000). Psychostimulant clinical response in fetal alcohol syndrome. *The Canadian Journal of Psychiatry, 45*, 90-91.
- Parr, J., Ward, A., & Inman, S. (2003). Current practice in the management of attention deficit disorder with hyperactivity (ADHD). *Child: Care, Health & Development, 29*, 215-218.
- Peadon, E., Rhys-Jones, B., Bower, C., & Elliot, E. (2009). Systematic review of intervention for children with fetal alcohol spectrum disorder. *BMC Pediatrics, 9*, 1-9. doi: 10.1186/1471-2431-9-35

- Rasmussen, C. (2005). Executive functioning and working memory in fetal alcohol spectrum disorder. *Alcoholism: Clinical and Experimental Research*, *29*, 1359-1367. doi: 10.1097/01.alc.0000175040.91007.d0
- Rasmussen, C., Talwar, V., Loomes, C., & Andrew, G. (2008). Brief Report: Lie-telling in children with fetal alcohol spectrum disorder. *Journal of Pediatric Psychology*, *33*, 220-226. doi: 10.1093/jpepsy/jsm069
- Riikonen, R., Salonen, Partanen, K., & Verho, S. (1999). Brain perfusion SPECT and MRI in foetal alcohol syndrome. *Developmental Medicine & Child Neurology*, *41*, 652-659. doi: 10.1111/j.1469-8749.1999.tb00518.x
- Riley, E., & McGee, C. (2005). Fetal alcohol spectrum disorders: An overview with emphasis on changes in brain and behaviour. *Experimental Biology and Medicine*, *230*, 357-365.
- Roebuck-Spencer, T., & Mattson, S. (2004). Implicit strategy affects learning in children with heavy prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research*, *28*, 1424-1431. doi: 10.1097/01.ALC.0000139826.25247.5B
- Sampson, P., Streissguth, A., Bookstein, F., Little, R., Clarren, S., Dehaene, P.,...Graham, J. (1997). Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopment disorder. *Teratology*, *56*, 317-326. doi: 10.1002/(SICI)1096-9926(199711)
- Sher, K., Grekin, E., & Williams, N. (2005). The development of alcohol use disorders. *Annual Review of Clinical Psychology*, *1*, 493-523. doi: 10.1146/annurev.clinpsy.1.102803.144107

- Sokol, R., & Clarren, S. (1989). Guidelines for use of terminology describing the impact of prenatal alcohol on the offspring. *Alcoholism: Clinical and Experimental Research, 13*, 597-598.
- Spandoni, A., Bazinet, A., Fryer, S., Tarpert, S., Mattson, S., & Riley, E. (2009). BOLD response during spatial working memory in youth with heavy prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research, 33*, 2067-2076. doi: 10.1111/j.1530-0277.2009.01046.x
- Steer, C. (2005). Managing attention deficit/hyperactivity disorder: Unmet needs and future direction. *Archives of Disease in Childhood, 90*, i19-i25. doi: 10.1136/adc.2004.059352
- Strade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C.,...Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost. *Canadian Journal of Clinical Pharmacology, 16*, e91-e102.
- Stratton, K., Howe, C., & Battaglia, F. (Eds.). (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment*. Washington: National Academy Press.
- Streissguth, A. (1997). *Fetal alcohol syndrome: A guide for families and communities*. Illinois: Versa Press.
- Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1996). *Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*. Seattle: Fetal Alcohol Drug Unit.

- Streissguth, A., Bookstein, F., Barr, H., Sampson, P., O'Malley, K., & Young, J. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Developmental and Behavioral Pediatrics, 25*, 228-238.
- Whaley, S., O'Connor, M., & Gunderson, B. (2001). Comparison of the adaptive functioning of children prenatally exposed to alcohol to a nonexposed clinical sample. *Alcoholism: Clinical and Experimental Research, 25*, 1018-1024. doi: 10.1111/j.1530-0277.2001.tb02311.x
- Willford, J., Richardson, G., Leech, S., & Day, N. (2004). Verbal and visuospatial learning and memory function in children with moderate prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research, 28*, 497-507. doi: 10.1097/01.ALC.0000117868.97486.2D
- Whitehurst, T. (2011). Raising a child with foetal alcohol syndrome: hearing the parent voice. *British Journal of Learning Disabilities, Published Online*. doi: 10.1111/j.1468-3156.2011.00692.x