Determinants of Drinking During Pregnancy and Lifespan Outcomes for Individuals with Fetal Alcohol Spectrum Disorder

Abstract

Fetal Alcohol Spectrum Disorder (FASD) has been identified as a major public health concern. However, limited research has used longitudinal data to track the developmental life course of these individuals. Furthermore, women who drink during pregnancy are not a homogenous group. Concerns regarding drinking behaviours in women who are or could become pregnant are therefore of great concern. The aim of this paper is to provide an overview of a number of risk factors that contribute to a woman’s drinking during pregnancy and FASD risk, as well as the subsequent lifespan outcomes that occur in individuals with FASD.

Prenatal exposure to alcohol is a common, preventable cause of developmental disability in the Western world (Connor & Streissguth, 1996; Public Health Agency of Canada, 2011; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008; Walker, Fisher, Sherman, Wybrecht, & Kyndely, 2005). In recent years, Fetal Alcohol Spectrum Disorder (FASD) has been identified as a major public health concern. The term FASD is an umbrella term that is used to describe a continuum of possible outcomes associated with prenatal alcohol exposure including: fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), fetal alcohol effects (FAE), and alcohol-related birth defects (ARBD) (Stade et al., 2009; Streissguth et al., 2004).

Individuals with FASD face serious challenges due to cognitive and behavioural deficits, such as attentional problems, cognitive impairments, and memory deficits. These primary impairments are the direct cause of organic brain damage due to prenatal alcohol exposure. Consequently, as a result of these primary impairments, otherwise referred to as primary disabilities, individuals with FASD have serious vulnerabilities for further difficulties in life, termed “secondary disabilities” (Streissguth et al., 2004). These secondary disabilities include mental health issues, legal problems, disrupted school experiences, inappropriate sexual behaviour, and addiction or substance abuse problems (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Streissguth et al., 2004). Despite the knowledge of these incredibly challenging difficulties, limited research has used longitudinal data to track the developmental life course of individuals with FASD and their families.

Although FASD influences all affected individuals in fundamentally the same destructive manner, culture, ethnicity, and social class factors all play a role in affecting the developmen-
tal patterns of individuals prenatally exposed to alcohol (Woods, Greenspan, & Agharkar, 2011). Women who drink during pregnancy are not a homogeneous group, and include women who are alcohol dependent, women who use alcohol on an episodic basis, and women who drink infrequently or regularly at low amounts (Public Health Agency of Canada, 2007). As has been well established in the literature, concerns regarding drinking behaviours in women who could become pregnant are also of great concern. According to the Canadian Alcohol and Drug Use Monitoring Survey (CADUMS; cited in Health Canada, 2011), among Canadians aged 15 years and older, the prevalence of alcohol use in 2010 was 77.0%. The prevalence of heavy, frequent drinking among youth aged 15 to 24 years old was approximately three times higher than the rate for adults aged 25 years and older at 9.4% versus 3.3%, respectively. Canadian statistics are also showing that the rate of heavy drinking for women, defined as consuming five or more drinks per occasion at least 12 times a year, is on the rise in Canada. In 2008, rates of heavy drinking were 9.6%, which increased to 9.9% in 2009, and 10.1% in 2010 (Statistics Canada, 2011a, 2011b, 2011c).

American statistics show similarly disturbing findings. For example, the Centers for Disease Control and Prevention (CDC; 2004, 2009) found that pregnant women most likely to report any alcohol use were: 35–44 years of age, college graduates, employed, and unmarried. Approximately 10.0% of pregnant women, or 1 in 10, reported any alcohol use in the past 30 days. 2.0% of pregnant women, or 1 in 50, reported engaging in binge drinking or frequent alcohol use in the past 30 days. Among women who might become pregnant, 52.4% said they wanted to become pregnant, 54.9% reported alcohol use, and 12.4% reported binge drinking. Other researchers have found comparable findings, such as Ethen et al. (2009) who found that drinking alcohol during pregnancy increased with age, from 19.0% among women less than 20 years of age to 37.2% among women aged 35 years and older. However, the pattern for binge drinking was reversed, with the highest amount of binge drinking reported among women aged 20–24 at 10.3% and lowest among women aged 35 years and older at 6.6%. Interestingly, the use of alcohol during pregnancy also increased with education, from 20.1% among women with less than 12 years of education to 37.1% among women with 16 or more years of education.

The question then becomes not who drinks during pregnancy, but why do women drink during pregnancy? Canadian findings show that in 2007 and 2008, the prevalence of drinking during pregnancy in Ontario, British Columbia, and Canada as a whole was estimated at 5.4%, 7.2%, and 5.8% respectively (Thanh & Jonsson, 2009). The authors concluded that in Quebec, Ontario, and British Columbia, in particular, alcohol consumption patterns have a more “Mediterranean” style, where individuals drink more often, drink wine more often than spirits, and drink more often with a meal compared to individuals in other parts of Canada (Canadian Centre on Substance Abuse, 2008; Thanh & Jonsson, 2009). Determinants and patterns of drinking are therefore influenced by other risk factors that can compound more than just alcohol consumption. Social, psychological, and biological influences likely play a role in determining who will drink during pregnancy. Therefore, the aim of this paper is to discuss the determinants of health (social, biological, psychological) that contribute to a woman’s drinking during pregnancy, as well as to discuss the subsequent life outcomes, framed within a lifespan perspective, for individuals with FASD.

**Search Strategy**

For the purposes of this paper, studies and review articles were identified through several sources, including various subject sources. Databases such as PsycINFO, PsycARTICLES, Annual Review of Psychology, Annual Review of Sociology, ProQuest Nursing and Allied Health Source, and PubMed were searched. Google and Google Scholar were used to identify conference proceedings or abstract publications that were relevant, since recent research in the field of FASD has brought to light the importance of taking a lifespan approach to understanding the outcomes associated with FASD. Relevant government sources, such as data published through Statistics Canada, was also used to identify specific information relevant to the Canadian population. Articles were selected on the basis of their relevance and
appropriateness to both the framing within a Canadian perspective, as well as their applicability to the specific issues at hand (e.g., cultural influences, genetic factors).

**Behind the Risk Factors: More Than Just Alcohol**

“Call them root causes, life conditions, and experiences or determinants of health...they are factors that set the stage for women’s use of alcohol during pregnancy” (Public Health Agency of Canada, 2005, p. 13). As so eloquently described by the Public Health Agency of Canada (2005), a number of factors can influence the likelihood of FASD, including family violence; poverty, unemployment, and homelessness; stress, and lack of knowledge of strategies for coping with stress; the role of alcohol in society; social pressures to drink alcohol and poor role models for some women; low self-esteem and social isolation faced by some women; and poor knowledge about the impact of alcohol. The risk factors for FASD could be described as puzzle pieces in a larger puzzle. The question becomes how do these determinants, the individual puzzle pieces, contribute to FASD individually, and how are these puzzle pieces, or determinants, inter-connected in developing FASD? A woman’s drinking during pregnancy does not occur in a vacuum, and an interaction of biological, social, and psychological factors influence their alcohol use.

However, according to May and Gossage (2011), detailed information on maternal drinking cofactors of risk is most often missing in many cases. Maternal risk is multidimensional, and there are a wide variety of variables that influence the development of an individual with FASD. Although a number of determinants influence the developmental patterns of FASD, four are briefly presented here.

**Nutrition**

Nutrition of the mother, both lifelong and during pregnancy, has been shown to be a significant factor in the amount to which the features of FASD are visible in the child (May, 2009; May & Gossage, 2011), and authors are increasingly acknowledging that pregnancy outcomes can be harshly compromised by suboptimal nutrition (Keen et al., 2010). Research regarding maternal nutrition has predominately come from rural South African studies. Results of these studies have revealed that both mothers and children have extreme nutritional deficiencies, which is undeniably one explanation for the very high rate of severe FASD in these regions (May & Gossage, 2011).

Researchers have noted that mothers of children with FASD have significantly lower intake levels of riboflavin, calcium, and docosapentaenoic acid (DPA), one of the omega-3 fatty acids (May et al., 2004), as well as zinc (Keen et al., 2010) and B vitamins (Tamura, Goldenberg, Johnston, & Chapman, 2004). Keen and colleagues (2010) found that a zinc deficiency was evident in mothers who drank in both Russia and the Ukraine compared to mothers who did not drink, as well as a copper deficiency in the Ukrainian sample. Research related to maternal nutritional status is still relatively new and researchers have been increasingly interested in determining how nutritional status can be a factor related to FASD damage. Maternal nutritional status is therefore important, and authors have suggested that suboptimal nutrition can potentially amplify the effects of other teratogens, particularly alcohol, in the developing fetus (e.g., Keen et al., 2010).

**Genetic Factors**

Although not fully understood, genetic factors emphatically play a role in FASD, particularly with regards to alcohol metabolism. According to Chudley (2009), we know that genetic influences play a role in FASD for two reasons. First, not all individuals who have been exposed to alcohol during fetal development show clinical effects. Second, animal research studies have shown that there are strain variances that are determined by differences in genetic background. Specifically, differences in the phenotypic presentation of individuals with FASD may be due to differences in genetic susceptibility (Chudley, 2009).

Chudley (2009) also acknowledges the high recurrence rate and risk of FASD within families (e.g., siblings, subsequent children, twins). For example, research has documented that siblings of children with FAS have an increased risk for FAS at 170 per 1000 among older sib-
lings and 771 per 1,000 in younger siblings, compared to 1.9 per 1,000 in the population as a whole (Abel, 1988). With regards to twins, research has shown that identical twins tend to be more similarly affected by prenatal alcohol exposure compared to fraternal or non-identical twins (Streissguth & Dehaene, 1993), indicating a genetic component to FASD expression. However, the greatest genetic influence for risk of FASD is likely with regards to alcohol metabolism (Chudley, 2009; Gemma, Vichi, & Testai, 2007). Variations in the functions of particular gene products or enzymes that may lead to alcohol cravings and alcoholism may increase a woman’s susceptibility to drink during pregnancy (Chudley, 2009; Ramsay, 2010).

According to research by May (2009), individuals who are lacking in alcohol dehydrogenase (ADH) and aldehyde dehydrogenase (ALDH) metabolism tend to drink less, and therefore have a lower risk for producing children with FASD. However, the inverse is also true, and individuals who have more ADH and ALDH may be at an increased risk of having children with FASD (May, 2009). However, it is essential to bear in mind that any amount of alcohol at any time throughout pregnancy can result in neurological impairments and central nervous system damage, regardless of drinking less or drinking more.

Race and ethnicity also appear to be factors, in that drinking patterns vary among different racial and ethnic groups. Additionally, research has indicated that there may be race-related physiological features, specifically the size of the mother, which may influence the rate and severity of FASD (May, 2009). However, it is again important to bear in mind that differences based on race and ethnicity may not be strictly genetic in nature, and drinking patterns likely vary based on cultural and social influences. Genetic features of both the fetus and the mother are not the only role that influences the presentation of FASD. The amount, timing, and frequency of alcohol consumed, as well as the overall state of health of the mother, in addition to the social, economic, physical, and environmental factors, also play a key role in FASD (Public Health Agency of Canada, 2005).

Despite what we know about genetic influences, the role of genetic variation in FASD remains inadequately understood (Ramsay, 2010). There remains no question that genetic variation has a role in FASD susceptibility, yet the nature and the magnitude of this genetic effect and its compounding interaction with other environmental factors remains unknown.

**Familial and Demographic Factors**

Social and psychological influences also play a crucial role in FASD risk. For example, engaging in binge drinking behaviour, coming from a family of origin of heavy drinkers, or having a partner who is a heavy or frequent drinker, can also increase a woman’s risk of drinking during pregnancy. Binge drinking has been found to be a damaging form of alcohol consumption on fetal development because it produces the highest blood alcohol content (BAC), and it is the peak BAC that affects the developing fetus most negatively (May & Gossage, 2011). Longitudinal studies (e.g., Jacobson & Jacobson, 1994; Streissguth & LaDue, 1985) have documented lower overall cognitive and behavioural regulation skills among children born to women who reported moderate or light drinking behaviours with infrequent binges. As outlined by May and Gossage (2011), mean intelligence quotient (IQ) and other cognitive measures indicate that cohorts of children born to mothers who drank during pregnancy are deficient when compared to children of mothers who did not drink. Therefore, quantity of alcohol consumed, particularly over a short period of time as in binge drinking, is a major factor in producing FASD. Timing of alcohol exposure is likely also important, since timing can influence anatomical features (e.g., FAS facial phenotype). In addition, critical regions may have key windows in time when damage can result from a heavy binge or chronic exposure.

Coming from a family of origin of drinkers is influential because this may influence a woman to begin drinking herself at an early age. For example, research by Astley, Bailey, Talbot, and Clarren (2000a) found that of birth mothers of children with FASD, most had begun drinking by age fifteen or earlier and 79.0% had come from a birth family where at least one parent had an alcohol problem.

Partners, particularly fathers, play a sizeable role in encouraging (or not encouraging) alcohol-free pregnancies. Specifically, fathers not only play
a role in encouraging alcohol-free pregnancies in their wives or girlfriends, but also in their daughters’ pregnancies (Gearing, McNeill, & Lozier, 2005; Leonardson & Loudenburg, 2003). As Bakhireva et al. (2011) state, “although paternal drinking per se is not thought to be teratogenic, to the extent that it encourages similar behaviour in the mother, it may represent a risk factor for FASD” (p. 537). This inter-generational connection is exceptionally important, as it provides a strong opportunity for breaking the chain of FASD within families.

A prospective cohort study, as part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD; cited in Bakhireva et al., 2011), analyzed cross-sectional data examining male partners alcohol consumption. Alcohol consumption among male partners was quite widespread; 15.1% consumed alcohol at least three times a week and 18.7% engaged in heavy episodic drinking behaviour. Furthermore, 29.5% of male partners were categorized as frequent drinkers, defined as consuming alcohol three or more times a week, or heavy episodic drinkers, defined as having five or more drinks per occasion. Not surprisingly, paternal drinking was highly correlated with maternal drinking during pregnancy; 51.2% of pregnant women continued to drink during pregnancy if their partners were heavy episodic or frequent drinkers, compared with 17.1% of women whose partners were not categorized this way.

Partner’s drinking habits are also important due to the connection between alcohol use and partner violence. Excessive alcohol consumption and alcohol problems in men are strongly linked to violence towards women (Leonard & Eiden, 2007). Being a victim of partner abuse, either physical or verbal, may influence a woman to drink as a means of coping and escape from the abuse. Partner abuse may further amalgamate previous experiences with abuse. Research from Astley et al. (2000a) found that 95.0% of birth mothers of children with FASD had been physically or sexually abused during their lifetimes. For those of us who do not have an alcohol addiction, we may believe the solution is simple: to just stop drinking. However, for women who have been victims of abuse and are continually sufferers in abusive relationships with alcoholic partners, it can be incredibly difficult to stop the cycle and quit drinking. Unfortunately, we as a society often neglect to acknowledge or take into consideration the social and psychological implications of a woman’s drinking behaviours.

Often discussed together, a woman’s socioeconomic status (SES) and educational level are also important demographic factors that influence one’s risk of having a child with FASD. The connection between poverty, ethnicity, and FASD is well established. Although FASD affects individuals from all walks of life and has been identified among all SES groups and nationalities, those who are the most disadvantaged by poverty bear the greatest burden of risk for FASD (Armstrong & Abel, 2000; Gearing et al., 2005). Research has shown that lower social classes have higher rates of FASD (Abel, 1995; Bignol et al., 1987; May, 2009; May & Gossage, 2011; National Institute on Alcohol Abuse and Alcoholism, 1994). However, there is a definite risk of FASD in middle-class, educated women who drink socially.

Studies have shown that the use of alcohol increases with increasing education and increasing income (e.g., Ethen et al., 2009). However, on the other hand, drinking behaviours in the same study were highest among those with lower education and lower income (Ethen et al., 2009). The implication here is that, although women of any SES or educational level can bear a child with FASD, women from lower socioeconomic standings are more likely to have children with the more severe forms of FASD: FAS and pFAS. However, women who are more highly educated and have a higher socioeconomic status, and drink socially, are more likely to have a child with FAE or ARND. Although their children may be less “severely” affected, this is often worse than having full blown FAS because individuals with FAE are often viewed as lazy or stupid due to their invisible disability and often go undiagnosed. Additionally, individuals with FAE or ARND tend to have average to above average IQs, and higher IQs than those with FAS (Jacobson & Jacobson, 2002). Individuals with FAS have IQs ranging from 29 to 120, with an average IQ of 79, but individuals with FAE have IQs ranging from 42 to 142, with an average IQ of 90 (Streissguth, Barr, Kogan, & Bookstein, 1997). Therefore, although individuals with FAE or
ARND have an average to above average intelligence, they are often at a greater risk for secondary disabilities due to society’s lack of understanding of their difficulties as a result of their organic brain damage.

Cultural Issues

Finally, cultures accepting of heavy drinking and alcohol-centred recreation (May & Gossage, 2011) create a significant risk for FASD. As scholars have previously acknowledged, the problem of maternal drinking during pregnancy cannot be separated from the pervasive culture that accepts and supports frequent, and often reckless, use of alcohol. For example, Miller and colleagues (2006), who examined the prevalence of FASD in Russian orphanages, recognized that alcohol use in Russia is excessive and the annual consumption of alcohol is among the highest in the world. Similarly, Italian studies of FASD have commented on the distinctive drinking patterns in Italian culture. Although binge-drinking behaviour is rare in Italy, in rural areas, daily consumption of “moderate” or marginally amplified amounts of wine with meals is so extensive that abstainers are rare, and the vast majority of women continue to drink during pregnancy (Ceccanti et al., 2007).

Perhaps still even more troubling is the ongoing myth that FASD is still believed to occur only in Aboriginal populations (e.g., Nanson, Bolaria, Snyder, Morse, & Weiner, 1995) and that, in some areas of the world, FASD is still not universally recognized. However, cultural influences are not the only determining factor of FASD. Some of these issues, such as culture and ethnicity, not only impact the initial development of FASD, but also compound further effects in individuals later in life. For example, as Woods et al. (2011) discuss, culture and ethnicity impact the social incompetence of individuals affected by FASD from poor minority backgrounds, which in turn has significant implications, especially in the criminal justice system (e.g., social intelligence and social competence). Therefore, it is essential to understand that FASD cannot be viewed in isolation from other potentially harmful behaviours or from the realities of women’s lives (e.g., poverty, low social support, abuse, SES) that the lead to the behaviour of drinking during pregnancy (Public Health Agency of Canada, 2005).

How Does Alcohol Affect Development? The Lifespan Outlook of Individuals with FASD

Prenatal alcohol exposure can have numerous detrimental effects across the lifespan (Connor & Streissguth, 1996). Unfortunately, a limited number of longitudinal studies exist mapping the outcomes of individuals affected by FASD (Sayal et al., 2009; Sayal, Heron, Golding, & Emond, 2007; Streissguth, Barr, Sampson, & Bookstein, 1994; Streissguth, Barr, Bookstein, Sampson, & Olson, 1999). Longitudinal data has outlined substantial neurological and neuro-behavioural deficits in individuals with FASD (Streissguth et al., 1994). In particular, longitudinal data has demonstrated problems with attention, memory, speed of information processing, and learning problems, especially arithmetic, in individuals with FASD between birth and age 14 (Streissguth et al., 1994). Additionally, antisocial and delinquent behaviours have also been observed in individuals with FASD (Streissguth et al., 1999).

Longitudinal data conducted by Sayal and colleagues (Sayal et al., 2009; Sayal et al., 2007) has also shown the connection between binge drinking and higher risks for mental health problems, especially hyperactivity and inattention. This is not surprising, given the findings of Streissguth, Barr, Kogan, and Bookstein’s (1997) study that demonstrated the high rate of mental health problems in individuals with FASD. Similar Canadian findings (e.g., Clark et al., 2004) have also established the common mental health diagnoses in individuals with FASD, with approximately 92.0% having a diagnosed mental health disorder. Additionally, Sayal et al. (2007) found that having one drink a week during the first trimester was associated with clinically significant mental health problems in female children at 47 months, a finding that continued to be shown at 81 months of age. This is a particularly important finding because it provides preliminary evidence that low levels of alcohol consumption during early pregnancy may have negative and persistent effects on later life mental health outcomes. Despite the limited number of longitudinal studies, numerous studies of individuals with FASD at different points in the life course can be pieced together to provide a lifespan perspective of potential...
outcomes. A summary of potential outcomes for each stage in the lifespan is presented below.

**Infancy and Childhood**

During infancy, infants with FASD often experience poor habituation, impaired reflex development, sleep disturbances (disrupted sleep/wake cycles), have a weak suckle, and have difficulties with attachment, which may be diagnosed as “failure to thrive” (Kelly, Day, & Streissguth, 2000; Olson, Jirikowic, Kartin, & Astley, 2007; Thomas, Warren, & Hewitt, 2010). Prenatal alcohol exposure is an early threat to the health of the child, which can cause issues related to personal temperament (e.g., poor bonding and forming of relationships), problems related to aggression or oppositional behaviours, and difficulties with poor or delayed social skills (Jones, 2004). Further, early bonding concerns may be particularly challenging for foster and adoptive parents. Throughout infancy, individuals with FASD may also be extremely irritable (Coles et al., 1991), and early central nervous system damage can make infants particularly vulnerable to highly stimulating environments due to their difficulty in tuning out redundant stimuli (Streissguth, 1997).

The toddler and preschool years of children with FASD are often referred to as the “golden years” of FASD (Streissguth, 1997). Children at this age are often quite inquisitive and eager to learn, although initial indicators of difficulties may begin to become evident. For example, children may begin to show their lack of understanding of “if-then” concepts, in addition to “lying,” and may often display some of their fearless tendencies. Because of organic brain damage to the frontal lobe, individuals with FASD have a number of executive functioning deficits, which lead to difficulties in a number of cognitive processes including planning, organizing, inhibition, working memory, set shifting, flexible thinking, and fluency (Rasmussen, 2005). Executive functioning abilities come around one year of age, with significant developments in executive functioning abilities between the ages of two and five. Adult-levels of some executive functioning abilities are reached by approximately age 12 (Rasmussen, 2005; Zalazo & Muller, 2002). However, children with FASD have been shown to demonstrate difficulty on tests of executive functioning compared to typically developing children (Kodituwakku, Handmaker, Cutler, Weathersby, & Handmaker, 1995; Mattson, Goodman, Caine, Delis, & Riley, 1999). These deficits in multiple areas of executive functioning explain many of the poor self-regulation behaviours seen in toddlers and young children with FASD, which continue on into adolescence and adulthood. However, as Rasmussen (2005) indicated, there is limited research on the development of executive functioning in individuals with FASD, which can have implications for comprehending how these deficits unfold from childhood through to adulthood. Based on the developmental trajectory of individuals with FASD, it would seem that many of these executive functioning deficits continue into adolescence and adulthood, and subsequently culminate in some of the secondary disabilities often present in individuals with FASD.

If parents or caregivers are unaware of their child’s prenatal alcohol exposure, some of these behaviours may seem endearing, particularly their lack of inhibition or lack of fear. For example, children with FASD may be incredibly sociable, friendly, and talkative, and may therefore be eager to speak with individuals they do not know. Although as a child this behaviour may appear cute, it is often an early warning sign of their inability to understand boundaries, discriminate between family members and strangers, and is an indicator of their naïve nature. Additionally, children with FASD may begin to show signs of their memory deficits, which can often interfere with children’s successful compliance with adult rules and requests. For example, children at this age may have difficulty following through with requests to clean their room or pick up their toys. Complying with rules and requests may be particularly troublesome for children with FASD because of their multiple step nature. Individuals with FASD often perform better when tasks are broken down into smaller components and one task is focused on at a time. Due to difficulties with working memory, individuals with FASD may have trouble keeping in mind the multiple steps that they need to follow. Furthermore, because of their difficulties in executive functioning, children with FASD often have trouble with transitions or changes.
due to their challenges switching between tasks and using mental flexibility.

As children move into school, the chain of events of the basic “cognitive, attention, and memory problems of children, adolescents, adults with FAS/FAE set the stage for behaviour problems in the classroom and at home because of repeated failure to meet expectations” (Streissguth, 1997, p. 134). Children with FASD are often overwhelmed by stimulation and are either unable to respond appropriately or protect themselves from this overstimulation. By third grade, academics usually becomes increasingly challenging for individuals with FASD, as concepts become most abstract in nature (Duquette, Stodel, Fullarton, & Hagglund, 2006; Streissguth, 1997). Streissguth et al. (2004) identified disrupted school experience as an adverse life outcome for individuals with FASD. In their sample, 42.0% of individuals with FASD had been in a special education classroom, 66.0% had been placed in a resource classroom, and approximately 65.0% had received some form of remedial help in the areas of reading and arithmetic. Mathematics is frequently discussed as a problem area for individuals with FASD, largely because of specific deficits in short term/working memory. Additionally, other features of learning, such as reading comprehension, higher-level language, and abstraction or metacognition may be problematic (Chudley et al., 2005) especially in the academic domains of English or language studies and mathematics. Therefore, due to learning disabilities in a number of areas, children with FASD may become increasingly more frustrated with school as they fall further behind their typically developing peers.

If a child who has FAE or ARND is not diagnosed, often teachers will believe that the student is lazy and that they could succeed if they only tried harder. Children with FASD may also show deficits in social skills at this age. For example, Thomas, Kelly, Mattson, and Riley (1998) found that children with FAS had deficits in social skills that were approximately three standard deviations below the mean for their age. Because of some of their emerging behavioural problems in the classroom or at home, in addition to difficulties with attention and impulse control, children with FASD are often diagnosed with attention-deficit disorder (ADD) or attention-deficit hyperactivity disorder (ADHD) in addition to FASD (Burd, Carlson, & Kerbeshian, 2007; Burd, Klug, Martsolf, & Kerbeshian, 2003; Dubovsky, 2009). Burd and colleagues (2007) estimated that a diagnosis of ADHD occurred in about 48.0% of children with FASD. Some individuals with FASD may in fact be misdiagnosed because their behaviours look similar to behaviours associated with other conditions, and often individuals with FASD are diagnosed with ADHD, oppositional defiant disorder (ODD), or a conduct disorder (Dubovsky, 2009). Children with FASD may have difficulties understanding personal space boundaries, in addition to difficulties making friends due to other challenges, such as their “stealing” behaviours.

Adolescence and Young Adulthood

Parents of children with FASD often describe the teen years like living life on a rollercoaster (Watson, Hayes, Coons, & Radford-Paz, 2013). Often by early adolescence, many of the secondary disabilities as described by Clark et al. (2004) and Streissguth et al. (2004), such as disrupted school experiences, trouble with the law, sexual promiscuity, mental health issues, and drug and alcohol problems, are beginning to flourish in individuals with FASD. An important protective factor that alleviates the consequences of secondary disabilities in FASD is living in a stable, nurturing home (Streissguth et al., 2004). However, a stable and nurturing home environment is not always the case for children with FASD, and these individuals often live in multiple foster homes throughout childhood. Additionally, research has found that only 20.0% of children with FASD live with their biological mothers (Astley, Bailey, Talbot, & Clarren, 2000b; Streissguth et al., 2004). Foster and adoptive parents are therefore often unaware of the birth mother’s alcohol consumption during pregnancy, which may lead to confusion in understanding their child’s behaviours, and further compound already existing difficulties.

Due to their neuropsychological issues, individuals with FASD continue to have learning and memory challenges, difficulties in problem solving, difficulties with planning, and psychosocial deficits, particularly maladaptive behaviours. As Streissguth (1997) outlines,
problems that teenagers face during this period are increased failure and less satisfaction in academic classes, more social isolation as peer interactions are dominated by cliques, uncertainty or unrealistic expectations about what it means to grow up, and a looming sense of low self-esteem and depression. Parents of children with FASD often express their hope that their children do not get in trouble with the law or become pregnant at an early age (Watson, Coons, Hayes, & Radford-Paz, 2013).

This is often an unfortunate reality for many individuals with FASD. By adolescence, many individuals with FASD have already experienced initial brushes with the law, likely for petty crimes such as shoplifting, and many individuals may be living on the streets. Often adolescence with FASD will run away from home or become involved with individuals who do drugs. By late adolescence, secondary disabilities are often in place and fully operating. Individuals with FASD may have a strong desire for a “regular” life and hope for a family and a stable job. However, often individuals with FASD will reach some level of self-awareness as to how their life may have fallen apart, but tragically they may not understand why they are unable to stay out of jail or maintain a stable job. Unfortunately, outcomes for individuals with FASD are often presented very bleakly, with little research documenting positive outcomes for those who are prenatally affected by alcohol.

Adulthood

Life experiences and life outcomes for adults with FASD is relatively non-existent in the literature. Adults with FASD have ongoing difficulties with adaptive and daily living skills and almost always need help with money management, medical care, productive work, and safe housing (Streissguth, 1997). As Bennett (2009) notes, the transition to adulthood for individuals with FASD should be viewed as a transition to “interdependence” rather than a transition to independence. Many individuals with FASD may not be prepared for independence and there are often deleterious outcomes, such as difficulties obtaining meaningful employment and incarceration that are often discussed by families (e.g., Watson et al., 2013).

Many challenges faced in adolescence continue into adulthood (Streissguth, 1997), particularly trouble with the law. As Woods et al. (2011) discuss, the prevalence of FASD is considerably higher for certain subgroups, and is alarmingly high for at risk groups, such as juvenile offenders (Woods et al., 2011) Surveys have found that between 15.0% and 20.0% of juvenile and adult offenders have FASD, but this is generally considered to be an underestimate. Furthermore, one consistent finding is that the social incompetence of young people with FASD becomes even more marked and disabling as they enter adolescence and adulthood (e.g., Streissguth et al., 2004). Therefore, some adults with FASD may reach some level of self-awareness of their different behaviour, such as violations of personal space conventions, which means that they often feel pain and sadness.

Individuals with FASD may also face serious challenges in life adjustment problems, specifically depression, alcoholism, crime, pregnancy, and suicide (Canadian Paediatric Society, 2002). Depression is the most common mental health problem in individuals with FASD, affecting more than 50.0% of adolescents and more than 40.0% of adults. Approximately 40.0% of adults and adolescents with FASD have made suicide threats and almost 25.0% have made suicide attempts (Streissguth et al., 1996). However, it is essential to conduct research on adults with FASD to obtain an accurate understanding of the lifespan implications of being prenatally exposed to alcohol.

Research by Grant, Huggins, Connor, and Streissguth (2005) indicated a poor quality of life among women with FASD. As adults, more than half of the women in their study lived in an unstable housing situation, relied on government assistance for income, and had previously been incarcerated. Additionally, 73.0% of their sample reported using alcohol or illegal drugs and 78.0% reported having a psychiatric evaluation, many of which had a diagnosis, indicating that adult women who have FASD have a poor quality of life and higher levels of psychiatric distress. Longitudinal data conducted in Germany also indicates similar negative outcomes for young adults with FASD, including intellectual disabilities or persistent cognitive deficits, limited occupational opportunities, and dependent living; the authors concluded
that the effects of prenatal alcohol exposure persist into early adulthood and severely limit careers and independent living (Spohr, Willms, & Steinhausen, 2007).

**Conclusion: Insights and Implications**

As Gibbard (2009) states, “it is remarkable to me, when I look at the literature on FASD, how rarely other cumulative factors are described” (p. 39). Rather than focusing on simply the consumption of alcohol, it is essential to understand the accumulation of risk that puts an individual in danger for having a child with FASD. As presented in this paper, understanding the sociological, psychological, and biological factors that are at play in women who consume alcohol while pregnant is essential in understanding the entire puzzle of FASD. Linear models are too simplistic for understanding developmental outcomes (Carta et al., 2001); therefore, there is a well-defined need for adopting a lifespan perspective to understand the outcomes of individuals with FASD. An individual’s trajectory can be altered by interventions, and those interventions can change the balance between prevention, promotion, and risk (Gibbard, 2009). Furthermore, accurate data on alcohol consumption among pregnant women, including prevalence and determinants and risk factors, is essential in designing and evaluating prevention programs (Thanh & Jonsson, 2010).

Despite decades of research on FASD, many professionals (e.g., doctors, psychologists, psychiatrists, teachers, and social workers) still remain ignorant to the devastating effects that prenatal alcohol exposure can have across the lifespan, both for the individual with FASD and their family. For example, a study by Clark et al. (2004) found that less than 60.0% of professional respondents, a sample that included family doctors, pediatricians, midwives, and psychiatrists, correctly recognized that a combination of growth, brain, and facial feature abnormalities provided the most accurate diagnosis of FAS.

Adopting a lifespan perspective to FASD is therefore critical in showing the destructive impacts of prenatal alcohol exposure on an individual’s life outcomes. By adopting a lifespan perspective, we are able to reveal and understand the enduring nature of FASD, and the subsequent developmental trajectories for these individuals. In doing so, hopefully we can provide targeted and tailored interventions at key stages. Early diagnosis, a helpful environment, and a variety of supports and services are needed in order to give individuals with FASD, their families, and their communities the best outlooks for improving outcomes and augmenting potential (Streissguth, 1997). By adopting a lifespan perspective, we are implementing a promising strategy for expanding the knowledge base surrounding FASD and enabling learning about the impact of FASD on the individual and the family throughout the lifespan (Public Health Agency of Canada, 2005). Only when communities adopt a lifespan approach to understanding and preventing alcohol-related disabilities can the condition truly be eliminated.

**Key Messages From This Article**

**People with disabilities:** You deserve to be accepted by everyone around you and to be able to access appropriate supports to help you throughout your life. You deserve to have people in your lives, such as family members, doctors, and teachers, who understand your disability and who can help you at all stages of your life. The people in your life should understand that your disability is caused by organic brain injury and not by you purposefully “acting out.”

**Professionals:** Having an understanding of the developmental trajectories of individuals with FASD is essential in helping them throughout their entire lives. Although binge drinking is a significant contributor to the presentation of FASD, professionals also need to be cognizant that even small amounts of alcohol consumption during pregnancy can cause devastating lifelong impairments.

**Policymakers:** Women who drink during pregnancy are not a homogenous group and a number of risk factors influence the presentation of FASD. Social, psychological, and biological influences all play a role in determining who will drink during pregnancy. Increasing the knowledge surrounding risk factors for FASD is essential in preventing misinformation and stigmatization.
References


