FASD: Moving toward sustainable assessment and support services in Ontario

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Abstract

Neurological, physical and developmental impairments resulting from prenatal alcohol exposure (PAE) fall along a spectrum and under the umbrella term Fetal Alcohol Spectrum Disorders (FASD). It is important to understand that FASD is in fact, brain damage. These disorders and their variations are complicated and often misunderstood. This often results in distressing outcomes, such as failed school experiences, trouble with the law, strained relationships, and home and placement breakdowns. The circumstances are often made worse by the lack of reliable screening, assessment and effective support services available to individuals and families across Ontario.

This qualitative study explored the impact of PAE, the assessment and support capacity within Ontario and ministry mandates that guide service provision in the areas of health, mental health, education and justice. An integrative review of the literature was undertaken and the results found that there are significant gaps in the current service delivery systems, but there are mandates that present viable options to consider in order to address the gaps and improve the circumstances for those affected by PAE. The findings led to three recommendations that address cross sectorial collaborations, policy development for FASD informed approaches, as well as professional development and prevention efforts. The implications for the field of social work are also presented.

Keywords: Fetal Alcohol Spectrum Disorders (FASD), Prenatal Alcohol Exposure (PAE), diagnosis, prevention, holistic care, FASD informed approaches, capacity building

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Chapter One: Introduction

What is Fetal Alcohol Spectrum Disorder (FASD), and why is there a need for diagnosis?

Alcohol consumed during pregnancy puts the fetus at risk of a multitude of deficits that fall under the umbrella term Fetal Alcohol spectrum Disorder (FASD). FASD is the leading cause of developmental disabilities in Canada (Public Health Agency of Canada, 2005). Dr. Paul Lemoin published the first research related to pre-natal exposure to alcohol in 1968. In 1973, the University of Washington published their findings about a number of children who shared facial anomalies and some level of delayed development. Similarly, there was a documented link made between delayed development, and pre-natal alcohol exposure (Chudley, Conry, Cook, Loock, Rosales & LeBlanc, 2005; FASD-ONE, 2014).

The term Fetal Alcohol Syndrome (FAS) was created to describe these children. As time went on, it was realized that the presence of the noted facial features resulted from alcohol exposure during a very small window of time during the pregnancy, specifically, between days 16-21 following conception (SAMHSA: FASDs Center for Excellence, 2007). This means that the way a child looks does not always reflect the degree of brain damage. Instead, this degree depends on many factors including but not limited to: time of alcohol consumption, quantity of alcohol consumed, frequency of alcohol consumption, genetics and protective factors. Protective factors in terms of pregnancy and infant development include such things as: maternal age, completion of high school, non-smoker, employed, within a coupled relationship, access to prenatal care, and good general mental and physical health (Chudley et al., 2005).

Currently, Fetal Alcohol Spectrum Disorders (FASD) is the umbrella term used to describe a range of deficits that result from pre-natal alcohol exposure (PAE). Included under this umbrella term are: (1) Fetal Alcohol Syndrome (FAS), (2) Partial Fetal Alcohol Syndrome (pFAS), and (3) Alcohol Related Neurodevelopmental Disorder (ARND) (Chudley et al., 2005). The assessment process, as recommended in the Canadian guidelines, consists of an initial screening process in order to rule out the likelihood that the symptomologies are due to causes other than PAE. Refer to appendix A for a detailed summary of screening tools utilized to help distinguish possible FASD from other behavioural and developmental difficulties and diagnoses. The screen also prevents assessments from moving forward for those without confirmed prenatal alcohol exposure (PAE). The diagnostic process following the screen and referral involves a physical examination, a neurobehavioural assessment, as well as treatment options and follow up. Team membership ideally consists of a physician, a psychologist, a speech and language pathologist, an occupational therapist, as well as a social worker and a clinic coordinator (Chudley et al., 2005). The process begins with a proper screen and ends with appropriate recommendations based on the findings. The Canadian guidelines for diagnosis also suggest that the team approach can vary in team composition and process depending upon the available resources, and the needs of the individual being assessed. Individuals who reside in the rural North, for example, may have to rely on tele-psychiatry or virtual teams, in order to have input from all of the required team members, as specialists are not always available in remote locations. These guidelines do offer options for optimal service delivery, but also allow for systems and communities to be flexible in terms of exactly how to operationalize FASD specific programs and services.

It is well known that alcohol is a toxin and that alcohol consumption during pregnancy is damaging (Chudley et al., 2005; SAMHSA: FASDs Center for Excellence. (2007); *Paton*, 2010). The structure and chemistry of the brain has forever changed during its development in utero as a result of the exposure to alcohol, which can lead to a myriad of serious lifelong difficulties. The benchmarks for the three specific diagnoses that fall under FASD are slightly different. The criteria for an FAS diagnosis includes evidence of prenatal or postnatal growth impairments, and simultaneous presentation of facial anomalies which include short palpebral fissure length, a smooth or flattened philtrum, and a thin upper lip. Additional to the physical features, there also has to be evidence of impairment in three or more central nervous system domains, which include: hard and soft neurological signs, brain structure, cognition, communication, academic achievement, memory, executive functioning and abstract reasoning, attention deficit/hyperactivity, adaptive reasoning, social skills, and social communication. A diagnosis of pFAS does not include criteria for growth restrictions but the individual needs to have simultaneous presentation of at least two of the facial anomalies associated with prenatal exposure to alcohol, and this exposure needs to be confirmed. The remaining criteria for FAS pertain to these individuals as well. Criteria for an ARND diagnosis are the same as FAS except it does not include any of the growth restrictions or facial features. Facial features are not indicative of the level of overall impairment (Chudley et al, 2005; Skerrit, 2008).

The primary disabilities associated with FASD are impaired intellectual functioning and developmental delay (Chudley et al, 2005; Kotrla & Martin, 2009). Individuals who have this disorder often present with speech and language difficulties, behavioural challenges, mental health issues, fine, gross motor and sensory issues, poor eyesight, and hearing difficulties, along with social skill and maturity lags. Because these individuals spend so much of their lives being misunderstood and significantly challenged, they are at an increased risk for secondary disabilities, which can be even more debilitating.

Secondary disabilities associated with FASD are not seen at birth (Malbin, 2002). Instead they result from the interaction between the primary disabilities and the environment, which can include family disruption, multiple foster or kinship care placements, attachment issues, as well as strained relationships that result from interaction with visibly frustrated and confused caregivers and education providers. This negative interaction often leads to numerous difficulties that may include, but are not limited to: mental health issues, education difficulties, interpersonal relationship difficulties, housing issues, and trouble with the law.

Research in this area continues to evolve, but it is understood that pre-natal alcohol exposure (PAE) is the leading cause of preventable mental deficiency in the western world (Popova, et al., 2013). Despite this fact, FASD and the risks associated with PAE remain poorly understood by health care providers and families (Alberta Health and Wellness, 2007; Astley & Grant, 2014). The effects of PAE are permanent, incurable, and can manifest as mental, physical, emotional, behavioural, learning and social deficits which compromise function throughout life (Chudley, et al., 2005). Those affected have a very uneven profile of skills and impairments, which usually include poor decision making skills, yet strong expressive language and a charming demeanour. They often present superficially as more capable than they are. When describing the effects of PAE, Dr. Jacqueline Pei, during an FASD symposium in London ON in 2012, compared the brain damage to a buck shot wound to the brain with the damage being scattered throughout, but leaving some parts of the brain untouched. The damage is scattered because the alcohol interferes with brain development when it is consumed and until it leaves the body (May & Gossage, 2011). When the alcohol is gone from the body, ongoing development continues as it would normally and healthily. This is why the individual can be extremely bright with specific talents, yet really struggle with other areas that inhibit learning and successful life experiences (Malbin, 2002). This presentation then can be very confusing to those around them and why it is often deemed to be an invisible disability (Mattson, Crocker, &

Nguyen, 2011; Michaud & Temple, 2013). The damage to the brain is very difficult to identify as anything different than bad behaviour and poor decision making skills and often assumed to be directly linked to poor parenting/caregiving practices. If undiagnosed, and consequently not properly supported, individuals with FASD often find themselves undereducated, unemployed, and disenfranchised from family, friends, and other supports. This, in turn, may lead to conflict with the law, mental health disorders, substance abuse, self-harm and other poor outcomes (Coons, 2013; Skerritt, 2008).

In spite of what we do know about FASD, the lack of diagnostic services has made the legitimacy of the disorders hard for many to accept. PAE is not a factor that is readily queried; and even if it is, many don’t follow through with the initial screening processes simply because there are not accessible diagnostic services in so many parts of the province (Burns et al., 2013; Chera, 2010; FASDONE, 2014). FASD is only just beginning to be incorporated in some post-secondary education programs; therefore, the up to date evidence has not been understood and/or accepted as true by many health and mental health care professionals (Paton & Croom, 2010; 2010; Skerritt, 2008). People are really struggling as a result. Pregnant women are still often not realizing the danger of PAE, and individuals experiencing the negative impact of PAE are very often misread (European Institute of Women’s Health, 2013).

The Invisible Disability: Implication of the disorder for individuals, families and communities

FASD is most often not easy to recognize, particularly when just observing physical characteristics. As seen in the photographs in Appendix B, many individuals with FASD do not have identifiable physical characteristics, and this false assumption is a contributing factor to the misinformation being shared among professionals and with patients/clients. Although there are some babies born with facial abnormalities and growth restrictions, the vast majority of babies born with FASD are not. It is surprising for most of us to learn that the facial anomalies can only take place within a period of 3-5 days in the very early stages following conception, which is before most are aware of the pregnancy. This means that the majority of those affected do not appear to be different (Popova et al., 2013). Difficulties associated with the disorder are not often easily distinguishable until the child attends school, and even then are often assessed to be a result of behaviour and parenting issues that will likely correct over time. Instead, however, these difficulties most often become worse over time until families are left heavily burdened.

Although each child is unique, there are some behaviours and areas of difficulty that are commonplace with those affected by PAE. These areas of difficulty are highlighted with available screening tools to help practitioners distinguish the difference between FASD, and other mental health or other developmental disorders (Chudley et al., 2005). See appendix A for an overview of the following recommended screening tools: Neurobehavioural screening tool; FASD screening tool for Probation Officers; and the Aboriginal screening tool. Some common FASD symptoms are: poor impulse control, dysmaturity, sleep problems, discrepancy between expressive and receptive language, hyperactivity, poor anger control, difficulty concentrating and learning new things and remembering things from one day to the other including the link between behaviour and consequences (Nash, et al., 2013).

Individuals affected by PAE are not waiting patiently and quietly in their bedrooms or classrooms for people to understand them and to better support them. They are experiencing real challenges and these circumstances, before proper screening and assessment, often result in caregiver distress, feelings of failure for the individual and the caregivers; and far too frequently, broken homes (Faulder, 2004; Olson et al., 2009). Caregivers are quite regularly bewildered, and exhausted, as are other natural and professional support networks and school staff in many cases. Typical parenting and discipline strategies do not work as they normally would with neuro-typical individuals. Without opportunities for proper assessment and diagnosis it is difficult to understand that when things go wrong the individual's behavior is not an act of willful defiance, for example, nor is it always within their control.

It is known that inadequate assessment services mean that prevalence rates are impossible to ascertain. Improvements and more targeted research efforts continue to evolve, and newer findings indicate that the prevalence rates appear to be much higher than we have understood them to be. According to recent research involving grade 1 students in a typical (not deemed to be high risk) Midwestern US state community, it was found that the total rate of FASD is estimated at 24 to 48 per 1000 children, or 2.4% to 4.8% (midpoint, 3.6%) (May et al., 2014). This statistic is higher than the standard 1% that has been widely documented as the prevalence rate for both the United States and Canada (Clarke & Gibbard, 2003). These individuals are utilizing support services, and providers in the helping professions are seeing them on caseloads and patient lists. However the services are not typically supporting them in ways that could provide the desired results. Instead, these vulnerable individuals are finding themselves in disrupted homes, on the streets, on income support programs, or worse yet, in our jail systems.

Ontario needs to do things differently. The government really can't afford not to. The total annual cost for individuals with FASD in Canada is currently estimated at 5.3 billion dollars (Stade, et al., 2009). Specifically, the service areas that incur these extra costs associated with FASD are found to be with healthcare services at 30%; educational services, at 24%; social services at 19%; correctional services at 14%; and other services outside of these parameters are at 13% (Thanh, et al., 2013). However, with earlier and more effective interventions and further prevention efforts, it is argued that this cost could be significantly reduced (Nguyen, Coppens, & Riley, 2011). Unfortunately, efforts made so far have not been able to convince Ontario government and funders of the long terms cost savings, both financial and emotional, which would result from the application of evidence based, targeted prevention, assessment and support services (Stade, 2003).

It is important to continually highlight that the effects of PAE on the developing fetus are significant and not clearly understood by the majority including service providers (Clarke & Gibbard, 2003; Kyskan, & Moore, 2005; Paton & Croom, 2010). Findings from pilot diagnostic clinics from London, Ontario indicate that direct and indirect involvement with the diagnostic process helps to facilitate more complete understanding of the complexities of FASD (Lundberg, 2014). This involvement also helps to alter support approaches that lead to better immediate and longer term outcomes. A timely and precise diagnosis is said to prompt parents and caregivers to seek diagnosis and support for previously undiagnosed siblings (Astley, Bailey, Talbot, Clarren, 2005). This means that quite suddenly the difficulties that have been observed in other children or family members makes more sense to those around them, and therefore the support approach can also be reformed immediately. This often will prevent further risk of compounded secondary disabilities.

Assessment clinic discoveries also indicate that families are desperately seeking accessible and relevant support (Lundberg, 2014). Families are articulating such gratitude for any services obtainable with an understanding of FASD, and the connection between caregivers and Clinic Coordinators has been profound (Lundberg, 2014). It is common to witness direct and indirect expressions of such a sense of “relief” to have someone who finally “gets it” in terms of the complexities of the disorders and the impact of the diagnosis (Denys, Rasmussen, & Henneveld, 2009; Lundberg, 2014). It has been demonstrated time and time again, that these families have commonly been left to their own devices and have been feeling misunderstood and blamed for their circumstances (Rasmussen, et al., 2012).

Chapter Two: Literature Review

Before advocating for increased diagnostic capacity, policy development, and system improvements in the area of FASD, it is important to understand with certainty the magnitude of the adverse effects of prenatal exposure to alcohol and the specific ways in which the effects present in individuals across the lifespan. This chapter summarizes the literature in this regard, and demonstrates that increased knowledge of how alcohol effects development is important as we continue working towards reducing the incidents of prenatally exposed babies, and improving the circumstances for those affected.

The Effects of Alcohol on the Developing Fetus:

The understanding of the dangerous effects of prenatal exposure to alcohol is not a new phenomenon. There has been awareness of the risks involved for centuries, as indicated by the following historically documented points. The Bible states, “Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks” (Judges 13:7). Clearly, it was understood by some, as far back as biblical times, that women who were of childbearing years should not consume alcohol and were advised quite explicitly. Physicians from centuries ago documented their understanding of the negative consequence to the unborn baby. In fact, the following quote from the College of Physicians, Great Britain, in 1726, is more emphatic than the style of which many doctors choose to express the risks of PAE to the unborn fetus today. “Parental drinking is a cause of weak, feeble and distempered children” (London Family Court Clinic, Child Parent Resource Institute, 2014). The unborn baby is in a state of continual development; therefore, it stands to reason that there has been damage linked to alcohol use in virtually every part of the baby’s body.

Alcohol is a toxin which can have the following implications on the developing fetus:

1. Alcohol can trigger cell death, which can cause different parts of the fetus to develop atypically.
2. Alcohol constricts blood vessels, and interferes with blood flow in the placenta, which impedes upon the delivery of nutrients and oxygen to the fetus.
3. Toxic byproducts of alcohol may build up and become concentrated in the developing brain and contribute to the development of an FASD (SAMHAS: FASDs Center of Excellence, 2007; Goodlett & Horn, 2001).

Table 1 below demonstrates the developing body parts and systems of the body and the times in which the particular focused development occurs.

Table 1 Stages of fetal development

Body Part/Organ	Period of development
Eyes	Weeks 4.5 to full term
Heart	Weeks 3.5 to 9
Lower limbs	Weeks 4.5 to 9
External genitalia	Weeks 7 to full term
Upper limbs	Weeks 4.5 to 9
Palate	Weeks 6.75 to 16
Teeth	Weeks 6.75 to full term
Ears	Weeks 4.25 to 20
Facial features	Week 3

(SMAHSA: FASDs Centre of Excellence, 2007)

This table demonstrates that alcohol will cause different problems at different times of development. For example, if no alcohol is consumed following week 9, then the baby's heart may be damaged, but his or her teeth and external genitalia could develop without any interference.

We know that there is no safe amount of alcohol to be consumed during pregnancy, but we also know that the risk of harm to the unborn baby increases as the amount of alcohol consumed increases (Burgoyne, 2006; Coons, 2013). Binge drinking, for example, is linked with higher risks of mental health problems such as hyperactivity and inattention (May et al., 2013). We also know that 92% of those with an FASD diagnosis also have a mental health disorder (Clark, Lutke, Minnes, & Kuntz, 2004). Even what might be considered small amounts of alcohol such as one drink per week, for example, has been linked to clinically significant mental health problems in female children at 47 months, and again at 81 months of age. This is very important research, as it provides preliminary evidence that even low levels of alcohol consumption during pregnancy can have detrimental and long lasting effects on health outcomes across the lifespan (Coons, 2013).

Impact across the lifespan

Infancy and early childhood. Infants who have had PAE frequently present with a high sensitivity to external stimuli, and are often extremely irritable and difficult to soothe (Goodlett & Horn, 2001). They regularly have a challenging time nursing as a result of a compromised suckle reflex. They are very often problem sleepers, with sensory issues that make it difficult to respond to touch and traditional bonding interactions as other babies would (Burgoyne, 2006). All of these symptoms can severely compromise the parent/infant bond, and further heighten the risk of transition difficulties for any new mother.

The toddler and pre-school years seem to be a timeframe of development that is most enjoyable and easiest to manage for families with children who have FASD (Coons, 2013). Children with FASD are most often not diagnosed and therefore not completely understood at this developmental stage. Their behaviour can be assumed to be within normal ranges (Malbin, 2002). They are generally quite inquisitive, have a desire to learn, a desire to please and seek indiscriminant social interaction and affection. These traits can be quite endearing, and not altogether different than other active children within this age group. However, children who have had PAE often have a difficult time with establishing boundaries and discerning appropriate, loving expression between family members and acquaintances for instance. They often are challenged in recognizing that it is not typical or safe to be seeking physical comfort and intimate conversations from strangers. Their ability to form and keep healthy relationships is already noticeably compromised (Healthy Child Manitoba, n.d.). This can be a warning sign as this speaks to their exaggerated vulnerabilities and their increased naïve tendencies. Additionally, it is in this developmental stage where caregivers may begin to notice slight indicators of learning difficulties. For example, their children may begin to show a lack of ability to recognize ‘cause and effect’ and ‘if-then’ concepts and may not be able to foresee dangerous situations or learn from them as other children would (Breen & Burns, 2012; Coons, 2013). This is also when caregivers may notice that their children will be telling what appear on the surface to be ‘lies’. Often in hindsight, this is when signs of problems may have first been observed in the following areas: memory problems, executive functioning, impulse control, organizing, flexible thinking and speech fluency (Mattson, Crocker, & Nguyen, 2011).

The challenge with screening, apart from the general lack of awareness regarding FASD, is that some of these difficulties can be missed or minimized by the parent and/or caregivers due to the varying degrees in which all kids meet developmental milestones within the early years. The brains of children within this age group are not developed well enough to manage complex tasks such as following multiple directions and remembering sequences. Research in the area of FASD over the last 30 years has clearly demonstrated that complex brain functions are what are most heavily impacted by prenatal exposure to alcohol. Pre-school aged children are not expected to write an essay, for example, nor are they expected to exercise good judgement independently, and to understand and participate in abstract communication therefore; it stands to reason that preschool aged children can look misleadingly well. It is not until much later when the expectations increase that the full impact of PAE is more pointed, and hard to ignore (Astley & Grant, 2014). Often time's individuals are reassured by professionals, which include family physicians, that their children are likely to 'outgrow' their presenting problems. The focus is often on behaviours and parenting styles, rather than the possibility of organic brain damage (Alberta Health and Wellness, 2007).

School age children. As children grow from toddlerhood and pre-school years, their difficulties often become more visible and, therefore, more problematic. The learning impairments, the difficulties linking cause and effect, the lying, the memory problems, and difficulties with executive functioning, impulse control and flexible thinking become more acute when the expectations of them increase. Simple tasks such as cleaning up their belongings, and their play area or bedroom may prove to be too difficult for children living with PAE to do independently due to their memory problems, and the step-by-step nature of the requests (Chudley et al., 2005; Malbin, 2002). Individuals with FASD do much better with one task at a time and for things to be broken down and simply instructed. However, clearly for a parent who is unaware of these special needs, the perceived non-compliance and lack of effort in terms of paying attention to detail, can be extremely frustrating (Denys et al., 2009). Children with PAE are also very concrete thinkers and see things quite literally. They appreciate routine and are typically less flexible in their thinking than most, which makes transitioning from one task or event to another very difficult most times (Institute of Health Economics Alberta Canada, 2009). The problems with attention and staying on task begin to present and result in further challenges, particularly when entering the school system and attempting to adhere to the rules within a busy environment with much stimuli.

By the time children enter the third or fourth grade, academics usually become increasingly more challenging. These demands are then exponentially higher for children with FASD because of the focus on abstract concepts and the expectation of independent work habits. Additionally, it is very common for children with FASD to experience disrupted home and school experiences which increases the risk of adverse life outcomes for this population. School experiences typically require significant support. In fact, Streissguth et al. (2004), demonstrated in their study that 42% of the students with FASD had been placed in a special education classroom, while 66% had been placed in a resource room, and close to 65% had received some form of targeting assistance for reading and math. Deficits with short-term and working memory are common with children who have FASD, which makes mathematical computations and problem solving particularly challenging. Higher level language, as well as reading comprehension and abstraction are also domains that are very commonly compromised, which further impedes the expected acquisition of many of the required academic concepts (Coons, 2013). The problems with cognition, memory, executive functioning, and attention pave the way for some very difficult behaviour problems within the classroom and within their home environment (Bredberg, 2011). It is difficult for these kids to understand why the world seems to be so confusing, and the reasons why they continually fail to meet expectations that their peers do, and why they are constantly frustrating other people.

Adolescence and Early Adulthood. Living with an adolescent with FASD is often described as being very difficult and often like a roller coaster ride: full of ups and many downs and going at a very fast pace (Badry, et al., 2009). The emotional cost to being misunderstood and trying to live successfully within environments that do not meet their special needs can be debilitating for many. As the biological age increases, so does the negative impact of the developmental difficulties that the individual is experiencing. This ‘poor fit’ most often results in the presentation of subsequent difficulties, which include but are not limited to disrupted school experiences, home placement breakdown, trouble with the law, sexual promiscuity, and problems with mental health and drugs and alcohol (Malbin, 2002). By the time the individuals reach adolescence, most of them have experienced increased difficulties with their peer group because they lack the maturity and social skills required in order to get along as equals (Clarke & Gibbard, 2003; Coons, 2013). The constant rejection plays havoc on their self-esteem, leaving them more vulnerable to depressive symptoms and a peer group, for example, that may lead them to unsafe circumstances. Parents and caregivers have become acutely aware of the high likelihood of these adolescents placing themselves in dangerous circumstances, and vulnerable to victimization (Chera, 2010; Coons, 2013; Leischner, 2002). Conversely, this lack of maturity and ‘childlike innocence’ often has a different expression. Research demonstrates clearly that it is common for these same individuals to be easily led into dangerous and law breaking circumstances due to their vulnerable and naïve tendencies. The results can be catastrophic. Many adolescents who have FASD find themselves involved with petty crimes and by the time they have reached mid-adolescence. Research states that 68% of those with an FASD diagnosis will have had some involvement with the law (FASDONE, 2014). There is a higher likelihood of placements breaking down and the individuals running away from safe environments and finding themselves couch surfing or living on the streets. The risk of drug and alcohol use and misuse is extremely high as well, which further compounds these difficulties (Caza, McLenna, & Mills, 2006).

These youth want what most youth want, and that is a ‘normal’ life involving a union of some kind, a warm home, a job, and most often some children of their own. However, they seem to know from time to time that these are not likely to be easily achievable (Chera, 2010; Denys et al., 2009). They often report their realization that their world is falling apart and that they are in need of some assistance, but in many cases the ‘poor fit’ they experience within their world makes finding successful associations very difficult (Malbin, 2002; Penner, 2005). They are often left feeling very deflated and puzzled.

Adulthood. The following quote describes a father’s challenges parenting his adult son who was diagnosed later in life with Alcohol Related Neurodevelopmental Disorder.

> In our effort to nurture the development of life skills for our son, we created routines and allowed for opportunities to practice new learned behaviours. When he was approximately 19 years of age, we were teaching our son to keep the house safe while we left the home. He practiced regularly and we provided non-judgmental support and guidance until he had it mastered. He was able to secure the home and remember the items he needed for his volunteer and vocational outside of home experiences. Because of the impaired ability to transfer learnings, he proceeded to lock the entire family out of the home on a Saturday afternoon while all were involved in a yard work project. (Dan Dubovsky, Waterloo FASD symposium, 2012).

This same FASD expert went on to engage the audience with humour, while reassuring others in the audience that it is okay to make parenting mistakes from time to time because as parents and caregivers of individuals with FASD there will be almost daily opportunities to re-teach similar skills and to “get it right”. Mr. Dubovsky maintained that a sense of humour, as well as a good support system for parents and family members is important to have because living and supporting individuals with FASD can be extremely difficult and emotionally draining.

The research specifies that the outcomes for adults with FASD who are not provided with appropriate supports are most often not very encouraging. In fact, as cited within *FASD: A call to action*, 2014, a study of individuals between the ages of 12 and 51, Streissbuth et al, (1996) found that only 18% of those with a known FASD diagnosis are able to live independently; 95% had mental health issues; only 20% were resided with their biological families; 70% experienced difficulties finding and maintaining employment; 68% had very difficult school experiences that at often resulted in a change or multiple disruptions; 68% of those studied were involved with the justice system, while many had been involved with inappropriate sexual behavior and substance misuse and abuse (FASDONE, 2014; Clarke et al., 2003). It is important to note that experts are recommending that the parents/caregivers/case managers shift their focus of support and goal setting to that of inter-dependence; reliance on direct and indirect support to accomplish tasks that most adults can do on their own, rather than the more typical model of independence (Breen & Burns, 2009; Clarke et al., 2003; Denys, Henneveld & Rasmussen, 2009). The lack of success with independent living occurs because organic brain damage is not repairable, yet in many cases the extent of this brain damage remains incompletely understood. The system currently does not have the capacity to properly screen and identify PAE, let alone diagnose for FASD. Therefore, it stands to reason then, that those who have been formally diagnosed at this time are more likely to be ones who have been more severely, and obviously affected by PAE with physical features for example, or with severe and notable learning and/or developmental disabilities (Ferrier, 2014; Goh, 2005; Harriman, 2008; May et al., 2014) . In these cases, it is more likely that the individuals are connected with FASD informed supports and services, and they have the advantage of being better understood and therefore supported more appropriately. This helps to mitigate the manifestation of problematic behaviour and secondary disabilities (Malbin, 2002; May et al., 2014). The life experiences of individuals with FASD are quite different for each, and the outcomes are much more positive for those who have been assessed and offered a diagnosis (SAMHAS: FASDs Centre of Excellence, 2007; Chudley et al., 2005).

Individuals with FASD can, and do lead very successful, happy, and fulfilled lives. There are tremendously talented individuals who experience a great deal of success in supportive workplaces with examples of accomplished electricians, teachers, counsellors, and skilled workers to name a few (Harriman, 2008). These success stories, however, are more apt to be told by individuals who have been understood, and who have been supported through an FASD informed approach. Unfortunately, without a diagnosis and proper identification of the individual’s unique strengths and areas of challenge, the individual is expected to adjust to the environment, and to accept the responsibilities that go along with adulthood independently. In an effort to better understand the personal impact of FASD, a Canadian Mennonite’s national correspondent interviewed a man with an FASD diagnosis named Russ, who was described as “a soft spoken, non-judgmental young man (Penner, 2005, pg. 1.)” Within this interview, Russ expressed gratitude for his early diagnosis. He believed that the early diagnosis allowed his adoptive parents to learn about the implications of the disorder, and thus parent and support him accordingly. He credits them for their commitment to understand, and indicated that he did well with the care and supervision that was provided by them. However, as he grew, societal expectations increased, while supervision naturally decreased over time. As a result, school and social experiences became more and more difficult for him which led to an early drop out in grade 10. By that time, Russ had already began to use illicit drugs and found himself involved with the criminal justice system. He went on to explain that family relations have been strained since, and his natural supports and friends have all “slipped away” (Penner, 2005, pg. 1). Also within this interview, Russ opened up about how he forgave his birth mother, but others still feel that he hangs on to some resentment for her, which in their opinion, may perpetuate his ongoing struggles. He admitted that it is difficult on him since FASD is preventable, it lasts forever, and he continues to struggle with addictions and he has spent the last 10 years in and out of jail. Russ acknowledged that times were better for him with the structure, support and understanding that was provided to him within the half-way house where he resided at the time of the interview. He spoke about securing full time employment and the benefits to his overall well-being as a result, but admitted to continual daily struggles “due to my continuing impulsivity, money management problems, lack of life skills and learning to live independently” (Penner, 2005, pg. 1). Russ’ description of his personal life experiences reinforce what the literature describes in terms of ongoing challenges in the areas of decision making, executive functioning, affect regulation, memory and processing skills, and the fact that these challenges often appear to magnify with increased age. Remembering things that they are responsible for such as; job start times; medical, and mental health appointments; feeding, and caring for children; and paying bills on time; for examples, can be very difficult for those experiencing FASD, yet to observers, these challenges could very easily be misunderstood to be a result of lack of effort, laziness and negligence. Individuals do better when they themselves understand their disorder, and when the people around them understand as well (Harriman, 2008; Malbin, 2002). The following quotes are available on the Asante Centre website which help to further illustrate the lived experiences of adults with FASD.

1. "I have a hard time keeping track of my belongings… like my bank card and my keys and even my beloved Walkman. When I picked up my prescription from the drugstore, I left my Walkman and coke. The manager called me and asked if I had forgotten them…. It's good to live in a small town… When I was growing up, people never thought of me as anything much…. When I look back on this time, I realize people didn't know I had FASD – either did I. I felt very lost and for me the world felt big and mean… When I found out I had FASD, I felt sad and was wishing that my brain was in good working order. Sometimes I feel like a scratched up CD or a messed up tape or like a guitar out of tune…. I am o.k., but my brain is not o.k. .we are real people and can still do lots of things…. We need more programs and more support… (Barb, aged 24.)
2. "Living with FASD takes a whole community to raise a child because they need a lot of tender loving care. They need people that have lots of patience and time…. I have three daughters who are 12, 9, and 6. I've been working as a homemaker. Every two weeks I pay the bills such as Hydro, natural gas, phone and cable." (Lucille, aged 32)
3. "I volunteer at the daycare for a couple days a week. I've done this for a few months now. During my job there I have a list of things to do so I don't get lost or wonder what else to do.….. it would be hard for me to have a full time job because of not being organized. (Val, aged 32) (www.asantecentre.org)

Many of the difficulties that adolescents experience continue on into adulthood including, involvement with the justice system, inability to maintain meaningful employment and inability to find and keep safe living conditions (Badry et al., 2009; Leischner, 2002). It is known that our incarcerated adult population is over represented by those who have been exposed to alcohol prenatally (Clark et al., 2004; Department of Justice, 2015). Although the research in this area is limited, our homeless population is also likely to be over represented by those with PAE, and many who have not had the opportunity to access FASD assessment services (Badry et al., 2009; Clark et al., 2004; Coons, 2013). Parents have significant worry regarding what the future might hold for their adult children. In order to demonstrate the impact of PAE, individuals with FASD are often viewed through a deficit lens. However, it is important to realize that there are tremendous strengths, and very often, untapped potential. Strengths that are associated with individuals who have FASD include a willingness to please, a desire for human connection, a desire to know and follow the rules, and to be helpful. Also, adults with FASD are very often non-judgmental, and have an exceptional ability to survive and adapt (Harriman, 2008). In order to support optimal outcomes, and to help adults with FASD reach their potential, the research suggests that individuals with FASD will require lifelong support which should include but not be limited to the following:

1. A circle of support networks that has regular involvement with the young adult and is committed to be involved for the long term;
2. Long term case management with a focus on advocacy to help facilitate understanding of the individual’s strengths and specific areas of challenge. This support person will be helpful if he/she continues to offer strength-based unconditional support to the individual experiencing FASD;

3. A stable source of income, which may mean assisting with neurodevelopmental assessments which highlight areas affected by PAE;
4. Additional support in completing application processes for income support programs and also supporting vocational training and opportunities;
5. A safe and supportive housing arrangement;
6. An immediate response to risky behavior and support and interventions to mitigate negative outcomes and consequences, for example, promiscuity, gang related behavior, vulnerability and desire to please tendencies, physical safety, medical care, mental health care.
7. Mechanisms to respond to crises, i.e. who is the ‘go-to’ person who will able to respond when there is a need;
8. Supported employment opportunities with FASD informed employees and contingency plans for areas of deficit such as, memory and planning difficulties and absenteeism.
9. Increased community awareness and access to community based services and supports (Badry, et al., 2009)

For those experiencing the effects of PAE, the period considered to be “youth” lasts significantly longer than for those with typical neurodevelopmental profiles (Astley et al., 2000; Badry, et al., 2009; Leischner, 2002). However, with proper supports such as the examples listed above, and realistic expectations, individuals experiencing FASD will have more successful outcomes and cognitive maturation will continue to develop overtime. Research indicates that an accurate diagnosis leads to proper understanding and therefore it facilitates more positive outcomes (Skerritt, 2008). When comparing families living with a variety of disabilities, research indicates that the struggles that individuals and families with

FASD face are distinct (Watson, Coons, & Hayes, 2013). A theme emerged from a qualitative study completed by Michaud and Temple in 2013, where the research focused on mothers' experiences raising a child with FASD. This study found that traditional parenting strategies and styles, do not apply when caring for a child with FASD, and this fact emphasized the difficulties in learning how to more effectively parent a child with FASD (Michaud &Temple, 2013). Parents need to reorganize their understanding of the difficult behaviour demonstrated by their child. They need to see it from a neurological perspective, and not see it as willful behaviour or a result of poor parenting (Bertrand, 2009; Malbin, 2002). According to Leon's Mom (as cited in Graefe, 1999), "Our lives would have been so much less complicated if all those born with A.R.B.D. (Alcohol Related Birth Defects) were also born with F.B.H. (Fluorescent Blue Hair.)

Chapter Three: Methodology

Purpose

This research project aims to help inform policy makers as well as education, health care, and social service program planners of the apparent gaps within the province of Ontario's current assessment protocols, and service delivery systems in reference to the needs of individuals and families experiencing FASD. Additionally, it is the intent of this project to provide clear and viable recommendations to help guide community, regional, and provincial FASD strategies. Social welfare and health related issues surrounding FASD cross over into many different Ministries. For the purpose of this project, it was important to research current priorities of the following ministries and help to determine where the needs of families as well as shared government mandates may intersect:

1. Ministry of Education
2. Ministry of Health and Long Term Care
3. Ministry of Children and Youth Services
4. Ministry of the Attorney General
5. Ministry of Community and Social Services

Setting

Ontario is the geographical area of focus for this particular study. This province is currently without a provincial strategy, and the research has demonstrated that Ontario has very few FASD specific assessment and diagnostic services as well as very few FASD interventions or supports (Chera, 2010; FASDONE 2014.) To illustrate this point, see figure 1 below that captures the formal assessment clinics across Ontario with connections to FASD ONE.

Figure 1. Map of Ontario depicting currently operational FASD assessment clinics across Ontario.

The map displays 13 assessment clinics that are formally acknowledged within our social welfare system and who are affiliated with the provincial FASD- Ontario Network of Experts Diagnostic Working Group. It is important to note that there is a new and comprehensive FASD program underway in Kenora which includes assessment and support services along with Ontario's first FASD classroom.

Research Question

Given the state of current FASD research and political realities that influence program development in the treatment of individuals with FASD impairments, this thesis question asks what may an optimal model for FASD assessment and support/interventions entail?

The related objectives are:

1. To explore areas of FASD assessment strengths and weakness in Ontario and in other jurisdictions to inform policy makers in Ontario.
2. Make recommendations that may guide the development of improved FASD assessment and support services for all Ontarians who could be impacted by pre-natal exposure to alcohol.

Method of research: An integrative review

This research project involves utilizing existing expertise obtained from findings from a wide variety of literature. Integrative reviews allow for the broadest type of research review which simultaneously includes both experimental and non-experimental investigation in order to be better able to understand a current concern or phenomenon (Knafl, 2005). An integrative research review is a valid research method that allows for the completion of a comprehensive review, analysis and summary of past research that comes in a variety of forms, i.e. journal articles, program evaluations, provincial strategies, organizational charts and plans, network policies and procedures et al. (Russel, 2005). This integrative review practise of examining the literature results in a solid understanding of the precise state of existing research and helps to guide the work and offers evidence based direction (Knafl, 2005). This process also assists to identify gaps and highlight where there is discrepancy in service delivery and equal access, and helps to identify future research areas. Integrative reviews have the potential to inform further research, as well as practice and policy initiatives (Knafl, 2005).

In addition, this integrative research review allows for opportunities to link bodies of research from different disciplines and further validates the benefit of working collaboratively, and thinking about the existing problem from different perspectives (Russel, 2005). In this particular research project, literature was linked and explored between Health, Social Work, Psychology, and Political Science disciplines. These perspectives from different disciplines are particularly helpful in the case of FASD since the symptoms and impact of the disorder do overlap and cross over to so many areas of social and health services (Alberta FASD Cross-Ministry Committee, 2008; FASDONE, 2014). In addition, the assessment process itself ideally involves a multi-disciplinary team that relies on the input from each member before a diagnosis is made (Chudley et al., 2005).

Rationale

An integrative review of the literature and research was completed in order to identify constructive methods for enhancing assessment and support services that are both cost effective and comprehensive, while adhering to Canadian Guidelines of Diagnosis and best practices. Because of the number of different disciplines involved in FASD assessment and support services, literature from different perspectives is seen to be vital in order to ensure that all clinicians and service providers feel that their scope of practice and expertise has been considered, and will be further called upon as the system grows (Chudley et al., 2005) An integrated review of existing research was embarked upon because, although FASD is not yet commonly understood or included in existing service delivery systems, there is plenty of research available to tell us quite clearly that it should be. Also, the research for this particular project involves looking at what is currently being done in other jurisdictions; primarily in Canada in terms of FASD policy and practice. This method of research enables the integration of the literature into policy discourse in order to come up with a viable plan for an FASD intervention strategy in Ontario.

The timing of this particular project is ideal since the province announced in January, 2015 that the Ministry of Children and Youth Services will facilitate community engagement sessions to gather input from experts (inclusive of academic, clinical, and caregiving expertise) as they begin to plan to develop a provincial strategy to address the complexities of FASD in terms of prevention, assessment and diagnosis, as well as support services across the lifespan for individuals and families. The results of this project will provide a meaningful contribution to the development of core funded sustainable FASD programs and services across the province.

Data Collection

Phase one.

The initial literature review, involved collecting existing peer reviewed literature within the current diagnostic environment and coordinating networks including FASD-ELMO and FASD-ONE. The research began with a thorough review of a local Needs assessment entitled, *South Western Ontario FASD Needs Assessment: Final Report* which was prepared by S. Chera, MSc, in December, 2010 for the Southwest Ontario Aboriginal Health Access Centre and the Thames Valley District School Board. I immersed myself in the research for several months prior to embarking upon this specific project. The focus of this initial research was to determine the impact of prenatal exposure to alcohol and to better understand the evidence of strength and challenge in this particular geographical area of the province.

A snowball sampling technique was then utilized that started with this needs assessment and then key data bases including, ResearchGate, CanFASD, and NoFAS, and FASDONE, in addition to contributions (news articles, formal studies and internal program evaluations and other examples of grey literature) made to the researcher by significant peer and expert informants. The literature began to demonstrate more broadly the impact of the disorder on individuals, families, and the various health, education, and social service systems overall. This literature also highlighted the level of need for individuals and families as well as current gaps in the area of FASD assessment and support services. Included in this dimension of the literature review was the investigation of various diagnostic models for FASD that are currently operational with the intent to further understand successes, challenges and opportunities for sustainability. This research involved exploring provincial strategies targeting FASD within Canadian provinces as well as two international FASD program examples. This background information provided context to move forward with exploring possible ways to enhance accessibility for those in need and to improve both efficiency, and efficacy for FASD targeted programs in Ontario.

The broad thematic categories that initially emerged from the literature review included: 1. Why a diagnosis? 2. Cost of FASD. 3. Government response and policy. 4. Models of diagnostic clinics. 5. Effects of FASD across the lifespan.

Phase two.

The second phase of this research involved studying peer-reviewed literature available through the Laurentian University library search engine which included journal articles, books, and dissertations. These items were found primarily within online Social Work databases, including SpringerLink, Sage Journals, and Social Work abstracts. Medical Sciences, including articles from the Canadian Medical Journal, PubMed, and the British Medical Journal as well as Psychology databases including PubMed, PsychInfo, and PsychArticles were also searched. The Google Scholar search engine was also suggested by peers for use to conduct more general searches. Key word search terms are indicated in Table 2. These library searches provided a wealth of research to be reviewed specifically about Canadian guidelines and practices of diagnosis, the experiences of families, and the need for assessment, risk factors, prevention strategies, system processes, collaborative approaches as well as behaviour and learning profiles.

Table 2 Summary of research searches

Source of data	Search Words for Report/Abstract/Article	Number of Data pieces Selected	key words/codes	Sub-themes
Laurentian University Library Social Work Psychology Medical Google Scholar	FASD diagnostics Cost of FASD FASD Knowledge of service providers FASD Family experiences Risk factors for FASD Prevention of FASD	37	Education and training Screening FASD informed practice Underestimating prevalence rates Invisible disability Family breakdown Prevention Stigma Training Wait lists Multi-disciplinary teams	need for diagnosis prevalence stigma need for support and services capacity building for clinicians and communities
Peer sources Newspapers Websites Policy briefs Journal of Developmental Disabilities	FASD diagnostics Cost of FASD FASD family needs FASD children in care FASD in justice FASD in education	57	Cost Secondary disabilities Respite and family support Treatment following diagnosis Misdirected services Lack of services Family support	Cost of DX Models of DX clinics Guidelines for DX Multi-disciplinary teams Support and services for those with PAE

The themes that resulted from the peer reviewed and examples of gray literature were as follows**: 1. Need for comprehensive multi-disciplinary assessments. 2. Prevalence, stigma**

and compounding issues 3. Cost of diagnosis. This particular phase of the research which identified the above mentioned themes further validated the need to explore what currently has been prioritized within various ministries, and what specific roles that each could have in terms of developing a targeted approach to FASD.

Phase three.

The third stage of the research involved a focus on the priorities of the Ontario ministries that are responsible for the education, and overall health and well-being of children, youth and adults. These ministries include: Ministry of Health and Long Term Care; Ministry of Children and Youth Services; Ministry of Attorney General; Ministry of Community and Social Services and Ministry of Education. The strategic priorities found within the mandate letters written from Premier Wynne to the respective Ministers form the foundation for the overall analysis which helped to define a structure around which to organize recommendations arising from the findings.

The priorities of these ministries and Premier Wynne’s mandate letters helped to identify themes that were later linked to the literature to indicate where FASD can fit into diagnostic and treatment systems. Table 3 below summarizes these ministry mandates and Premier priorities.

Table 3 Ministry Priorities and Premier Directives

Ministry	Mandate priorities	Consolidated themes for analysis across identified ministries
Ministry of Children and Youth Services	1. Transforming the Child Welfare system 2. Providing opportunities for at-risk youth 3. Building strong relationship with our Aboriginal partners 4. Promoting the mental health and well-being of Ontario’s children and youth 5. Supporting children and youth with complex Needs 6. Reducing poverty 7. Developing and implementing initiatives focused on early identification, early intervention and responsive programs and services for families of children and youth with special needs.	1. The need for equal access, and inclusion for those in need. 2. Collaborative, coordinated and integrated programs and services with a focus on accountability and efficiency are necessary. 3. Improved mental health and wellness focussed supports and services for individuals and families.
Ministry of Health and Long Term Care	1. Putting patients at the center 2. Moving forward on accountability and transparency 3. Collaborating on shared responsibilities across government 4. Lead the second phase of the mental health and addictions strategy to support coordinated, timely and quality services	
Ministry of Education	1. Moving forward on child care and early years 2. Achieving excellence 3. Ensuring equity 4. Promoting well-being	
Ministry of Community and Social Services	1. Transforming Social Assistance and Development Services 2. Collaborating on shared responsibilities across government	
Ministry of the Attorney General	1. Ensuring a fair and accessible justice system for all 2. Building a stronger relationship between First Nations and the justice system 3. Building safer communities 4. Reforming the family law system	

The integrated analysis occurs by taking the findings from the first two phases of the literature review and integrating them in accordance with the stated ministry priorities as articulated through their mandate letters.

Reflexivity

This research is of particular interest to me because I am currently coordinating a pilot FASD assessment clinic in London Ontario. The need for increased services and direct funding and commitment from agencies, policy makers and government leads is observed every day. Emotional pleas are heard daily from caregivers and individuals who are experiencing compounded difficulties with very few resources available to them. Professionally, this is very trying work and the risk of burn out is high. I am hired to coordinate the clinic, and I was also tasked to build clinician and assessment capacity for the London and surrounding areas. What was not anticipated, however, was the additional demands placed on this position simply from the volume of referrals and telephone call requests for crisis support and consultation and training opportunities on a weekly, and sometimes daily basis. Nor was I able to anticipate the resistance to change, and frankly the demonstrated lack of awareness, and sometimes, even interest from many health, education, and social service providers and administrators with regards to better addressing the needs of this vulnerable population. This is not a new problem. My very first professional experience over 20 years ago, involved supporting a young boy with FAS. I feel that our social service and health care systems should be much further ahead in terms of adequately addressing the complex needs of those affected by PAE. I have been keenly interested, and have continued to build expertise in this area through direct contact with those experiencing the effects of PAE through a variety of education, health and mental health institutions, as well as through ongoing professional development opportunities. It is my hope that in the not-so-distant future, families will not need to advocate so hard, and that individuals experiencing FASD will be better understood and more intentionally and strategically included within the Province of Ontario’s health, education, and social welfare systems.

Chapter Four: Findings

A comprehensive and integrative review of the literature has clearly determined that it is vital that Ontario improves system delivery in the area of FASD. Ministry mandates, position papers and vision statements were explored to help to identify where responsibilities lie in terms of assessment and support services for individuals with PAE. At this point in time, the responsibility to lead FASD initiatives seems to lie nowhere directly or certainly consistently across the province, yet, understanding and supporting individuals with complex needs is a part of many health care and social service job descriptions in one way or another.

Having identified the overarching Ministry priorities, and the fact that FASD clinical assessment and interventions currently remain largely excluded from the service delivery system in Ontario (FASDONE, 2014; Breen & Burn, 2012; Peadon, Rhys-Jones, Bower, & Elliott, 2009), this section integrates the research, and detects where FASD fits within identified ministry mandates and existing strategic plans. The combined and overarching government priorities from the Ministry of Education, the Ministry of Child and Youth Services, the Ministry of Community and Social Services, Ministry of the Attorney General and the Ministry of Health and Long Term Care, are as follows:

1. The need for equal access and inclusion for those requiring medical and social services.
2. Collaborative, coordinated and integrated programs and services with a focus on accountability and efficiency.
3. Improved mental health assessment and wellness supports and services for individuals and families.

These overarching priorities are what forms the framework for analysis. Within each overarching priority, a more detailed look at the specific ministry priorities is further expanded upon and these priorities are linked with what the research is indicating in terms of FASD specific issues for individuals and families. This chapter provides the evidence required to guide recommendations aimed at address the apparent gaps across health, education and social service systems.

1. The need for equal access, and inclusion for those in need of medical and social services.

This first priority indicates that all of the ministries that were studied for this research project view the ability to access services to be critical in order to keep people well, and to help people reach their potential. Services need to be inclusive, with efforts made to reduce barriers to various system services. The following quote from her mandate letter to the Minister of Children and Youth Services is an example of the government of Ontario's commitment in this regard: "Your priority will be to work with your ministerial colleagues, so that every child and young person in Ontario has access to the right supports and opportunities needed to make positive choices, reach their full potential and seamlessly transition to adulthood." Nevertheless, the research indicates that there are significant gaps in this area for those who are experiencing the effects of PAE. As FASD advocacy and diagnostic efforts persist, and new FASD interventions and programs emerge, people are becoming increasingly aware of the issues and needs of those affected by PAE. This heightened awareness directly results in more pressure to meet the need and a responsibility on the part of policy makers to do things differently (CanFASD Northwest's Network Action Team on Diagnostics, 2011). To help put this into context, most would agree that it would be unethical for a practitioner to dismiss the symptoms of diabetes or depression, for examples, simply because the practitioner did not believe the patient or understand the symptoms. In terms of this shared priority of equal access and inclusionary practices, each ministry has specific priorities and responsibilities that are outlined below. Following these priorities, are further findings of related gaps and opportunities to consider for policy changes.

Ministry of Children and Youth Services (MCYS):

Priorities: Regarding the need for equal access and inclusionary practices, the MCYS has the responsibility to ensure that all children, youth, parents and caregivers, including those with special needs, have access to a flexible continuum of timely, comprehensive and appropriate services and supports within their own cultural and environmental community context. Premier Wynne indicated in her mandate letter, sent on September 25, 2014, that this ministry will be inclusive of FASD going forward. Premier Wynne stated the Ontario government will target efforts, "focussing on developing and implementing strategies that will improve the experience and outcomes for children and youth with complex and special needs, including Autism Spectrum Disorder (ASD) and Fetal Alcohol Spectrum Disorder (FASD)." This priority also specifies the need for accessible services and that initiatives need to be developed and implemented that focus on early identification, and early intervention for families of children and youth with special needs.

Gaps and Opportunities: The review of this literature indicates that for a variety of reasons, there are significant gaps in terms of FASD specific supports and services that this Ministry provides, therefore equal access is a significant issue (FASDONE, 2014).

Individuals who are affected by PAE often present in crisis to mental health agencies to address the presenting behaviour and emotional symptoms. To date, FASD has been one of the most invisible of disabilities, virtually excluded from the majority of current service delivery systems. Until such time that service providers are better able identify and support those affected by PAE, individuals and their families will continue to be essentially left on their own, struggling to make the world make sense. Addressing the needs of people experiencing FASD in varying degrees is within the scope of practice for those in the helping professions: however, there is a general lack of both awareness and confidence on the part of service providers to do so effectively and comprehensively (Breen & Burns, 2012; Chera, 2010). Targeted education and training efforts to allow for adjustments to be made to service delivery approach is one way to address these gaps. As mentioned within the literature review, without support and understanding, the risk of secondary disabilities is much higher and most often compounds the individual's neurodevelopmental challenges (Chera, 2010; Chudley et al., 2005; Popova, et al., 2012).

Ministry of Education (M of Ed):

Priorities: Regarding the need for equal access and inclusionary practices, the Ministry of Education has prioritized their role in inspiring all students from early years to adulthood to reach their full potential. Premier Wynne stipulated that there needs to be concerted effort made to close achievement gaps for those at risk of not succeeding and that her focus for education is on "equity" (Wynne, 2014). Those deemed to be at highest risk include: Aboriginal students, students who are in foster care, newcomers, and students who have special education needs. Research indicates that neurobehavioural disorders associated with PAE are estimated to be the largest preventable cause of intellectual disabilities, speech and language disorders, ADHD, mild intellectual disability, and specific learning disorders (Bell & Chimata, 2015). The correlation between PAE prevalence rates within this targeted high risk student population means that those affected by PAE are many of the children and youth that the Minister of Education is to prioritize in terms of closing the achievement gaps. This ministry has also been directed to enhance public confidence in the education system's ability to provide optimum learning environments with excellent outcomes for all students.

Gaps and Opportunities: In order to be successful in providing equal access and inclusionary services for all students, it is imperative that individual learning needs are identified and that each student has equal access to supports, program modifications, and accommodations that address their unique learning needs. For students with PAE, access to FASD informed special education services is critical and often dependent upon a diagnosis. "For children, the focus is always school. They can get recognized as exceptional by having an FASD diagnosis, and be entitled to service to help maximize their opportunities and likelihood of success there" (Chera, 2010, pg. 10). However, in light of the limited FASD assessment and support interventions in this province, the fact is that many students who are experiencing difficulties directly related to PAE, do not have access to the most appropriate services. Additionally, even with a diagnosis, the current list of exceptionalities set out in subsection 1(1) of the Education Act, and elaborated upon in *The Individual Education Plan (IEP), A Resource Guide* (2004) does not include

FASD, which can be problematic for school programming. It is difficult because targeted FASD accessible educational support is currently dependent upon the level of interest and expertise within the particular school - and these levels tend to lack consistency across communities, and boards of education.

Unfortunately, there have been many discouraging examples where individuals and families have been misunderstood, and sometimes blamed for their circumstances (Bertrand, 2009; Bredberg, 2011; Faulder, 2004). Insufficient support often results in school disruptions, failures and early exits.

In an effort to clarify the duty of educators to adequately accommodate the needs of those experiencing FASD, and other disabilities within exceptionality protocols, Barry Finlay, the Director of Education submitted a memorandum to the Directors of Education, the Supervisory Officers and Secretary-Treasurers of School Authorities, the Director of Provincial Schools Branch, the Superintendent of Centre Jules-Leger. Within this memo, Mr. Finlay clarified that:

> The ‘guide is intended to be interpreted broadly, and not in a manner that excludes any barriers to learning apparent upon individual assessment… Inclusion of some medical conditions (e.g., autism) in the Guide’s definitions of the five categories of exceptionalities (behaviour, communication, intellectual, physical and /or multiple) is not intended to exclude any other medical condition that may result in learning difficulties, such as (but not limited to) Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD), Fetal Alcohol Syndrome, Tourette Syndrome, Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, and Fibromyalgia Syndrome. (Finlay, 2011, p. 1)

This memo from Mr. Finlay also explains that access to special education services is not diagnosis specific, but rather based on the needs of the individual, which in turn is based on the individual assessment of strengths and needs. In order to ensure accessible support services, the assessment protocols have to be more inclusive to determine, if applicable, complex neurodevelopmental disorders (FASDONE, 2014; Ministry of Children and Family Development, 2008).

While the Minister of Education is to continue to build on her work to promote equitable, inclusive, and accepting school climates, examples from the Southwestern Ontario FASD Needs Assessment, indicate that there needs to be improvements in order to achieve these outcomes, and to improve public confidence.

> When students with FASD are able to access appropriate educational supports, they have positive academic experiences and outcomes… However, the lack of recognition of FASD within the education system as a whole means that in schools where administrators and educators are less knowledgeable of FASD, students and caregivers experience difficulty in accessing adequate educational supports… Our child requires a modified program with one on one EA (Educational Assistant) for the classroom and he has a right to one, but he does not qualify for one under the Board of Education or they do not have the funding, etc. After three years of battles with the school and him falling apart and further behind, we needed to pull him from public school… to attend a private school that could address his needs… (Chera, 2010 pg. 10, 11)

Individual education plans and support services need to be inclusive of FASD in order for families to feel confident that their child has access to equitable educational opportunities.

Ministry of Attorney General (MAG)

Priorities: Regarding the priority for equal access and inclusionary services for those in need, Premier Wynne outlined very specifically that the Honourable Madeleine Meilleur, the Minister of the Attorney General is responsible for ensuring a fair and accessible justice system for all (Wynne, 2014). In order to provide fair access to the justice system, the person's mental health and capacity to understand consequences and to follow through with recommendations needs to be understood. Without this understanding of the individual's potential and limitations, there is significant risk that the justice system will not consider alternative processes and supports that he or she needs in order to reduce the likelihood of recidivism, and to keep the individual and community safe. The MAG is also responsible for the protection of the Ontario public under Ontario's Human Right's code. This code speaks very directly to the need for fair and equitable treatment and for opportunities, programs, and services to be accessible to all (Ontario Human Rights Commission, 2009).

Gaps and opportunities: Equal access and inclusionary services for individuals and families experiencing FASD and who are involved in the justice system is not realized nearly enough. Given that the prevalence rates of PAE within our child welfare system and youth justice system are much higher than the general population (Badry et al., 2009; Clark et al., 2004; Goh, 2005; National Organization on Fetal Alcohol Syndrome, n.d.), these numbers represent a significant proportion of who this ministry understands to be ‘at-risk’ youth. The lack of access to FASD screening and assessment within the social service and medical systems, overall, means that holistic and developmentally appropriate supports are not put into place to mitigate the risk of the involvement of the criminal justice system. Once individuals find themselves there, the system is often unable to adequately address the specific issues properly, let alone, to decrease recidivism. Recommendations through pre-sentence reports et al., rarely consider the implications of a neurodevelopmental disorder, therefore, they are not likely to lead to the desired outcomes. “Since FASD is not always visibly identifiable, youth and adults with FASD often present as ‘normal’ to police officers, judges and others within the criminal justice system, and are inappropriately incarcerated” (Chera, 2010, pg. 12). This combination results in our justice system being disproportionately occupied by those who have had PAE and are at risk of FASD (Badry et al., 2009; Leischner, 2002).

Employees of the justice system, which include Crown Attorneys, have indicated that there is a greater urgency for assessment and support services for children and youth who are at risk of being involved in the justice system, since an accurate diagnosis has the potential to change the course of a youth’s life. A diagnosis can take them completely out of the criminal justice system, through youth therapeutic court, and mental health diversion programs, for example. However, with such limited access to assessment and support services, justice professionals have to guess which kids have organic brain injury (Chera, 2010).

If these youth were better understood within the social welfare system, they and their families would have access to respite, supportive housing, case management and therapeutic alliances that would be FASD informed. Research indicates that the risk of justice involvement would therefore be reduced if these less expensive, and client centered supports were put into place (Cook, Green, Salmon & Stewart, n.d.; Coons, 2013; FASDONE, 2014). Time spent in detention is actually detrimental for many children/youth with PAE because of the brain injury, and also due to the frequently co-existing issues with attachment and trauma (Clark et al., 2004). School based prevention projects, diversion projects, youth therapeutic court, as well as attendance centres have been operational since the instigation of the Youth Criminal Justice Act (YCJA), and are aimed at providing more therapeutic and customized supports that allow for structure, routine, restitution and healing, with the hope to reduce recidivism (Caputo &Vallée, 2007). However, these programs are not currently equipped to operate efficiently or effectively with youth who have less obvious developmental disabilities - specifically, those affected by PAE.

Accommodations need to be made for those with a disability, but it is argued that the Human Rights Code is impossible to uphold in light of the overall lack of understanding of the ‘invisible’ disability of FASD and consequently, the exclusion of FASD informed approaches across various health, education, and social welfare systems (Breen & Burns, 2012).

Ministry of Community and Social Services (MCSS):

Priorities: Regarding the priority for equal access and inclusionary service provision, Premier Wynne specified to the Honourable Helena Jaczek, MCSS that this Ministry is to promote accessibility to supports that are high quality and person-centered. This ministry is also tasked to ensure that more individuals in need have access to affordable housing. The fundamental goal of this ministry is to transform the delivery of developmental services to promote as much independence as possible for individuals with complex needs, and to provide training and vocational opportunities that would result in skill development and meaningful contributions to their community (Wynne, 2014). Premier Wynne prioritized greater independence for people with complex needs by encouraging work and access to sustainable supports outside of the social assistance system.

Gaps and opportunities: The transformation of the delivery of developmental services will not be complete without service providers more commonly recognizing FASD as a developmental disability. This will not happen without access to more timely and comprehensive diagnostic services. In order to meet eligibility criteria for developmental services and for Ontario Disability Support Program, an applicant needs to provide the results of a psychological evaluation that indicates specified areas of deficit.

> If the individual is 18 years of age or older and does not have a psychological assessment or report by a psychologist or psychological associate but the documentation provided indicates the presence of a developmental disability (e.g., school or medical records), the Application Entity will facilitate referral to a ministry funded agency for assessment by a psychologist or psychological associate to determine whether the individual has a developmental disability as defined in the Act and regulation. (Ministry of Community and Social Services [MCSS], 2013, p. 3)

This is important information for transitioning youth and their families to be aware of, as typically, many who have had PAE, and are struggling with expectations of daily living, live with fear as they prepare to enter adulthood without a proper diagnosis (Chera, 2010). A diagnosis is required before individuals have access to the most relevant supports such as intensive case management, counselling and mental health support, supportive housing, modified and supportive vocational opportunities, and family respite. Without one, the current system assumes that the difficulties that these individuals face are behavioural and matters of personal choice, which does not meet eligibility criteria. Again, the typical average I.Q. camouflages the individual's true areas of deficits (Dybdahl & Ryan, 2009; Chera, 2010; Chudley et al, 2005).

Families have been voicing their need for assistance with transitional planning (Breen & Burns, 2013; Chera, 2010; FASD ONE, 2014). In July 2014, the non-partisan, cross sectorial Select Committee presented their final report entitled, *Inclusion and Opportunity: A New Path for Developmental Services in Ontario,* to the Speaker of the Legislative Assembly. This report includes various recommendations aimed at improving the circumstances for individuals and families in need of developmental services. These committee members were committed to consulting with various stakeholders across the province and they were privy to very personal stories, which indicated that many individuals and families who need developmental services and supports are in crisis. They also learned that families are often left on their own due to wait lists and exclusionary criteria, and at times services are only available to them once they are forced into crisis. This is part of the story for many families experiencing FASD as indicated throughout the literature (Breen & Burns, 2012; Chera, 2010). The process was admittedly troubling for the committee members who believe that everyone has the right to full social inclusion and to have access to services without delay (Select Committee on Developmental Disabilities, 2014, p. 3). Although the recommendations for the entire report applied to everyone with special needs (which include FASD), the needs surrounding FASD were specifically addressed. “There will be a coordinated provincial strategy to address FASD through appropriate and timely support services in all communities and regions, including a province-wide public health campaign to raise awareness of the dangers and impact of maternal alcohol use” (Select Committee on Developmental Services, 2014, p.13). Unfortunately, such a coordinated strategy is not yet in place.

As a result of the overall lack of awareness and insufficient diagnostic services across the province of Ontario, access to equitable supports and services is not often possible, and many are left to struggle on their own and without the required financial and emotional supports. Transitioning from high school to early adulthood is an area that needs special consideration for individuals with FASD. It is becoming more widely recognized that beyond financial supports, there is also need for lifelong and consistent supports for people experiencing FASD (Breen & Burns, 2013; FASDONE, 2014). Instead of focusing on skill building toward independence, a focus on interdependence seems to be what is most effective for those experiencing the effects of PAE. Current services could be modified to be inclusive of the needs of transitioning youth and adults who are experiencing difficulties with confirmed PAE.

By way of example, the Lakeland Centre for FASD developed a tool kit to help guide this process in Alberta (Badry et al., 2009). In this tool kit there are areas identified to target in order to address FASD specific needs. These targets are as follows:

1. A support network that has regular involvement with the youth
2. Advocacy casework focused on supporting the strengths of individuals with disabilities while managing areas that need extra assistance.
3. A stable source of income
4. Supportive living arrangements
5. Responsiveness to risky behaviour
6. Mechanisms to respond to crises
7. Supportive employment, volunteerism and/or participation in day programming
8. Community access and awareness

The above mentioned priorities would help the Ontario government ensure that adults experiencing the effects of PAE, and/or FASD would have access to equitable (relevant and helpful) support services. The MCSS has a responsibility to ensure that applicants for Developmental Services Ontario (DSO) which is the umbrella coordinating service provider for individuals with developmental disabilities, including income support/ODSP are properly assessed.

The Honourable Dr. Helena Jaczek presented the Select Committee on Developmental Services with a response to their recommendations for system improvements and transformation. She indicated that eligibility for Developmental Services Ontario does require that criteria are met (MCSS, 2013). However, she specified that eligibility does not rely on IQ alone and that if an individual continues to struggle with the activities of daily living, yet standard psychological tests do not provide the results that would typically qualify a person for DSO, then the clinical expertise of a psychologist or a psychological associate could be called upon. This clarification now allows inclusion of those individuals requiring financial and social support because they are not capable of gaining and keeping meaningful employment due to limitations in the areas of cognitive functioning and daily living/habilitative skills (MCYS, 2013). As a result of deficits in the area of adaptive function, research from Olson et al., 1998 (as cited by Clarke and Gibbard, 2003) indicates that less than 10% of adults with FAS live independently despite having average, to low average, intellectual abilities.

Ministry of Health and Long Term Care (MHLTC):

Priorities: Regarding the need for equal access and inclusionary service provision, Premier Wynne in her mandate letter to the Minister of Health and Long Term care in September, 2014 indicated that she expects the MHLTC to ensure that people have timely access to the most appropriate care, in the most appropriate place and at the right time. This priority also speaks of using the capacity of all service providers, hospitals, community clinics, long term care homes etc. to ensure that there is not duplication and that the patient’s care is underway and coordinated no matter where they enter the system and identify as needing care. The Premier directed this Ministry to provide faster access to specialists, and relevant health care. This government promises to provide faster access to the right care by bringing health care providers together and by integrating a variety of allied health providers into family health practice, i.e social work, and physiotherapy et al. (MHLTC, 2014). Dr. Eric Hoskins has introduced the next Action Plan for health care in Ontario in February, 2015. It focusses on holistic care, reducing barriers, faster access to specialists, and the commitment of those in charge to work toward improvements in the system as a whole, and more equitable and inclusive services to all who are in need.

> Our plan is called “Patients First” because caring for people is what motivates everyone in the health care sector, from doctors and nurses to administrators and personal support workers. The desire to improve people’s lives was at the core of why we chose this vocation and it must be at

> the core of every decision we make as a health system. Who we are and what we stand for as a society that values human life, that believes in dignity and respect for all...these are essential not only to health, but to the health care sector as a whole. A commitment to equity and access and universality – these are not just lofty ideals; these are principles worth striving for and defending always. (Hoskins, 2015, p. 1)

Gaps and opportunities: Despite the focus on equal access and inclusionary service provision, the health care system in Ontario has some work to do in order to see improvements in this area, particularly for those with PAE. Given that the majority of medical providers have a very limited understanding of the risks and impact of PAE, and that our health care system lacks capacity to adequately address the needs of this population, access to FASD assessment and support services of any kind, at any point of health care entry is not happening as it should (Alberta Health and Wellness, 2007; Bredberg, 2011; Clarke & Gibbard, 2003; Ferrier, 2014). This priority speaks to the diverse clinical and administrative roles within healthcare, and the typical intrinsic motivation for those working within the health care field to improve people’s lives. It speaks to the need to be inclusive and a reminder to all that each health care employee has significant roles to play and all could have a significant impact on the patient. However, it also highlights the importance for all health care staff to be made aware of hidden disabilities such as FASD to avoid unintentionally perpetuating difficulties for some. For example, an administration staff at a hospital may inadvertently escalate a volatile situation by not realizing that an individual’s response may be due to developmental, rather than solely behavioural challenges. Research findings indicate that these typical responses and biases need to be challenged (Breen and Burns, 2012).

The MHLTC indicates that it is committed to providing equal, accessible, and universal diagnostic services. Therefore, efforts made to better understand FASD would allow for proper screening, assessment and referrals to take place at the community level would be ideal (Adnams et al., 2007). This type of health care service, focusing on prevention and early identification, would have significant positive impacts for families experiencing possible FASD, and this would also reduce the likelihood for individuals and families utilizing emergency rooms and mental health hospital services (Alberta Health and Wellness, 2007; Astley, Bailey, Clarren & Talbot, 2000; Bredberg, 2011; Breen & Burns, 2012) .

Services need to be inclusive, yet the research indicates that for a variety of reasons, this is not the case for those who are experiencing PAE. The introduction of the Canadian Guidelines for diagnosis (Chudley et al., 2015) has led to an increase in awareness of need, and also an increase in demand for services. As diagnostic efforts persist, and new clinics emerge, the heightened awareness directly results in pressure to meet the need (CanFASD Northwest's network Action Team on Diagnostics, 2011). Access to diagnosis is necessary in order to offer relevant and helpful treatment and support options, and research indicates that the earlier that a diagnosis is made, the better it is for the individual and family (Chudley et al., 2005; Popova et al., 2013).

In summary, individuals who have been exposed to PAE enter the health, education, or justice systems at a variety of places; all of which have clear priorities and mandates that are developed in order to ensure that those in need are adequately understood and supported. A strategic approach to increase service providers' capacity in the area of awareness and prevention, assessment and diagnosis, as well as treatment and support services would lead most directly to improved outcomes for those affected by PAE. Unfortunately, as it stands in Ontario right now, research indicates that the system is failing those experiencing FASD and that a targeted effort needs to be made to ensure that existing services are, in fact, inclusive of all those in need.

2. Collaborative, coordinated and integrated programs and services with a focus on accountability and efficiency.

This second priority indicates that these ministries believe in, and are insisting upon cross-sectoral collaborative and coordinated efforts. FASD is a neurodevelopmental disorder that crosses over many ministerial domains. This condition results from pre-birth interference that needs to be addressed sensitively in terms of prevention and mitigating further risks, and ideally by a medical provider during regular pre-natal care. The condition continues to impact development throughout the lifespan, which prompts the involvement of a variety of different service providers and system supports. The need for holistic care and a 'wrap-around' approach for children with complex needs has been clearly demonstrated (Badry et al., 2009; Breen, & Burns, 2012; FASDONE, 2014). All ministries have limited budgets, and there has been increasing public pressure to be transparent, fiscally responsible, and accountable to the people of Ontario. Premier Wynne speaks directly to these points on the second page within her mandate letter to the Minister of MCYS, the Honourable Tracy Mac Charles on September 25, 2014:

> As we move forward with our plan to grow the economy and create jobs, we will do so through the lens of fiscal prudence. Our 2014 Budget reinforces our commitment to balancing the budget by 2017-18; it is essential that every area adheres to the program-spending objectives established in it. We will choose to invest wisely in initiatives that strengthen Ontario's competitive advantage, create jobs and provide vital public services to our families. The President of the Treasury Board, collaborating with the Minister of Finance, will work closely with you and your fellow Cabinet members to ensure that our government meets its fiscal targets. The President of the Treasury Board will also lead the government's efforts on accountability, openness and modernization as we implement new accountability measures across government. (Wynne, 2014, pg. 1)

It seems clear that the ambitious mandates of various ministries will need to be met on very tight budgets.

The Ontario government is particularly interested in integrating new ideas into existing infrastructure where possible. There have been fundamental, overarching principles among Ontario's Ministries for decades, regarding the need to work collaboratively, and share existing resources in order to improve the desired outcomes and efficiency of programs and services (MCYS, 2006; Brown, 2012; MCYS, 2013; Wynne, 2014). Although FASD specific assessment and support services are in their infancy stages across the globe, there are established models that Ontario policy makers can learn from. All of the provinces west of Ontario have inter-ministerial, nonpartisan provincial strategies in place, while Ontario currently does not. Simply put, the Ontario government has not yet made any financial commitments toward a coordinated and consistent approach for FASD. Table 4, below, summarizes the provincial commitments and strategies within Canada.

Table 4 Comparing provincial financial and strategic commitments across Canada

Provincial strategy	Province population	Examples of Financial investment	Ministries involved	Strategic Priorities
FASD: Building on Strengths. A provincial plan for BC 2008-2018	4.63 million	In 2006, Ministry of child and Family Development established a 10 million dollar action fund	Cross gov’t committee from: Children and Family Development, Public Safety and Solicitor General, Health Services, Health Planning, Education, Advanced Education, Human Resources, Attorney General, Community, Aboriginal, and Women services, department of Justice Canada, Human Resources Development Canada	Citizens are aware of the risk Women and partners have access to early intervention Pregnant women with addictions have access to focussed interventions Access to timely diagnosis Services are coordinated, integrated and research based Access to lifelong supports Diagnosis: Complex Developmental Behavioural Conditions (CDBC) Network
Alberta FASD 10 year Strategic Plan 2008	4.2 million	$16.5 million annually since 2008-2009	Alberta Cross-ministry com. Aboriginal Relations Advanced Education and Technology Children and Youth Services Seniors and community Supports Education Health and Wellness Employment and Immigration Justice and Attorney General Solicitor General and Public Security	Awareness and prevention Assessment and diagnosis Supports for individuals and caregivers Training and education Strategic planning Research and evaluation Stakeholder engagement Diagnosis: 12 FASD service networks are a key initiative of the FASD 10 year Strategic plan to provide community based coordinated diagnostic services
Sask. From Dependence to independence:	1.13 million	3.8 million annually	Cross ministerial committee on ASD and FASD from Social Services and provincial child and youth agenda	Prevention Supportive programming Diagnostics: Presently available in Regina, Saskatoon, and Prince Albert, Community and mobile clinics
Together We Are Stronger: Building Manitoba’s FASD strategy	1.28 million	10.5 million annually	Inter departmental committee Health Living, Youth and Seniors Education/Health/Justice Family Services and Consumer Affairs Aboriginal And Northern Affairs Housing and Community dev Healthy Child Manitoba Office	Prevention Support and services for pregnant and post-partum women Assessment and diagnosis along with support for individual and their care givers Service providers understand the impact of FASD and use best practices Diagnosis: FASD network with 5 coordinators who work with Manitoba FASD Centre for a diagnosis and to develop community based clinics
Ontario	None	13.68 million	$0. Dedicated towards coordinated efforts	Diagnosis: 14 official clinics with varied funding sources.

New Brunswick	None, however, MOH commitment lead process	755 464	$500 000 annually	Plans underway for a Center of Excellence in Moncton Regional Diagnostic Clinics and resources throughout province aimed at improving prevention and support strategies as well

While it is important to deliberate the gaps and areas of challenge, it is encouraging to see opportunities for change and the documented political priorities that seem to lend themselves quite naturally to the current FASD specific needs. The compounding issues surrounding FASD, are cross-sectoral and multi-faceted. As a result, a collaborative, inter-ministerial and strategic approach is seen to be vital in order to effectively address FASD. The table above indicates that other provinces have made significant progress working collaboratively across ministries.

Ministry of Children and Youth Services

Priorities: On September 25, 2014, Premier Wynne wrote a letter to Minister Tracy MacCharles with priorities for her to focus on as Minister of Children and Youth Services. Regarding collaborative efforts, efficacy, and accountability, Premier Wynne spoke of the government's responsibility to be cognizant of financial investments and the returns. There is a commitment on the part of this Premier to invest in children and youth and the coordination of quality, inclusive and relevant services. Premier Wynne also emphasized the need work collaboratively, to provide a seamless continuum of services to young people and their families into adulthood. The Premier spoke of partnerships, collaborations, and engaging communities and businesses in order to foster continued economic growth, and to make a positive impact on the lives of every Ontarian.

The MCYS has recently initiated planning stages for the development of an FASD provincial strategy. This is a clear indication that this Minister sees the value of a shared responsibility, and is well positioned to develop plans that will ensure efficiency and accountability in the area of FASD.

Gaps and opportunities: With regards to collaborative efforts, efficacy and accountability, addressing the complex needs of FASD requires a sharing of resources and a collaborative approach, in terms of multi-disciplinary, and holistic services, as well as cross sectorial collaboration to provide a continuum of care across the lifespan (FASDONE, 2014). To highlight the need for collaboration, the assessment process itself is comprehensive, time consuming and requires the involvement of multidisciplinary team preferably comprised of a physician, a speech and language pathologist, an occupational therapist, a social worker and a psychologist (Chudley et al., 2005; Fryer, 2005). These clinicians and services do exist within our social service and health care systems, and with training, FASD could be very easily included within the repertoires. What complicates the process at times, is that often these clinicians are funded from different agencies and ministries (Chudley et al., 2005). A multi-disciplinary team approach is the recommended best practice because PAE can affect a number of physiological as well as neurodevelopmental/behavioural domains and symptoms overlap with other medical and mental health disorders. Consequently, the individual will require the supports from a variety of different agencies and ministries: mental health, developmental services, education and justice, for examples, throughout the lifespan (Chera, 2010). Collaborative and coordinated efforts are required in order to build system capacity and to plan ways in which to integrate some of the assessment and support services into existing models of care (Healthy Child Manitoba Office, n.d.).

Using the most conservative approach, it was estimated that an FASD evaluation requires 32 to 47 hours for one individual to be screened, referred, admitted, and diagnosed. This process results in a total cost of $3,110 to $4,570 per person (Popova et al., 2013, p. 1). Given that coordinating existing resources is a priority, doing so would lend itself to more efficient and accountable service delivery.

It is imperative to acknowledge that the cost to children with puzzling learning and memory problems, challenging behaviours and misdirected treatment planning is exponentially higher than the estimated cost of comprehensive FASD assessments (London Family Court Clinic, Child Parent Resource Institute [LFCC, CPRI], 2014). For consideration, a chart was reviewed, and the cost of a FASD London Region referral is presented within appendix C. This estimated total of $94 000 includes all services accessed from 0-9 years of age for this particular child, that were aimed at understanding her complex and severe behavioural and mental health issues - before the query of FASD was brought forth. The vast majority of this misdirected funding came from MCYS services which included residential treatment, parenting support, psychological and occupational therapy assessments. If the query of FASD had been made earlier, this child and family could have been better understood and supported more appropriately. Doing so would have likely reduced both system costs and emotional burdens. In cases such as these, charts can be reviewed by FASD informed diagnostic clinicians, and the combined findings from existing assessments can sometimes lead directly to an FASD diagnosis, which enables a more complete understanding of the difficulties presented. In other instances, criteria may be met by augmenting prior findings, rather than repeating measures and starting anew. This method of utilizing existing reports simply makes good business sense, all the while being less intrusive and more supportive for the individual and family. Better yet, would be the ability to provide proper interventions from the first time that the individual presents with concerns.

Research evidence directs us to improve our screening for PAE, and reporting of FASD (Chudley et al., 2005), and the confirmation of PAE can be disclosed and reported more readily by a provider who is engaged in a therapeutic relationship with the biological mother. Integrating the screening process for FASD into existing children's mental health and developmental assessment and early interventions processes would help to identify and support more individuals and families as the point of system entry.

Families also would like to trust the system to coordinate itself and to support the whole family and not just the child. They are admitting that at times they wish for service providers to "hold the parent's hand" while they are busy holding the hand of their child(ren) (MacCharles, 2013). Families have expressed that coordination is critical; and therefore, it is time to focus on system enhancements and pooling resources in order to better understand and address the needs of families with special needs, including FASD. This understanding cannot happen without being better able to differentiate FASD from other behavioural and mental health disorders. A seamless and client centered approach would be most welcome to this vulnerable population (Bertrand, 2008; Breen & Burns, 2012; Chera, 2010; FASDONE, 2014). Collaborative, coordinated and integrated programs and services are a priority of the MCYS, and the evidence surrounding the complex needs of individuals and families experiencing FASD would benefit from this type of approach as their needs to cross over many ministerial domains.

Ministry of Education:

Priorities: With regards to collaborative efforts, efficacy and accountability, Premier Wynne wrote in her mandate letter to Honourable Liz Sanders that the Minister of Education is to focus on achieving excellence. In fact, “Achieving Excellence: A Renewed Vision for Education in Ontario” is the title of the policy framework that is to guide the next steps. The Ministry of Education has been directed to continue working with other ministries in order to assist with transitions to ensure that all students, notwithstanding their conditions, can be supported in the ways that are most helpful and relevant (Wynne, 2014). In her mandate letter to Minister Sandals in September 2014, Premier Wynne also speaks of the focus over the next decade to be on continual improvements in learning opportunities to ensure that young people have the talent and skills that they need to enter the workforce, and to ensure that our young people are prepared to lead in the global economy. The Premier indicates that the long-term plan for the education system is to have integrated services from early years to adulthood (Wynne, 2014). This is consistent with the Ministry’s desire to increase the public’s confidence in the publically funded education system (Ministry of Education, 2014).

School boards have a desire to inspire all their students to achieve their learning potential. In order to do this, the Ministry of Education invests significant resources into multidisciplinary special education services in order to assess students in order to develop relevant education plans.

Gaps and opportunities: With regards to collaborative efforts, efficacy, and accountability, problems exist because so often the developmental delays and difficulties for those who have had PAE are camouflaged and interpreted as behavioural and mental health issues. These missed opportunities make it difficult to plan appropriate services for these individuals, and hinder efforts made to improve system efficiency and accountability (Ferrier, 2014). Individuals affected with PAE are often seen as very challenging learners, who are ‘treatment resistant’ and can legitimately be very frustrating for caregivers, teachers, and service providers alike, adding to the cost burden (Breen& Burns, 2012;

Bertrand, 2009; Malbin, 2002). Consequently, teacher and clinician response will remain insufficient so long as we do not have the ability to screen appropriately, and to offer diagnostic services or those in need (CanFASD Northwest's Network Action Team on Diagnostics, 2011). Unfortunately, parents and families experiencing FASD have expressed clearly that they lack confidence in the school's desire and ability to adapt the teaching environment in order to better address the unique challenges presented (Chera, 2010; Kotrla & Martin, 2009). As previously noted, emerging research findings indicate significantly higher prevalence rates than previously assumed, ranging from 2.5 to 5 children out of 100 (May et al., 2014). This means that 1 in 20 students may very well be affected, amounting, on average, to one student per classroom.

Early Years programs and services offered within school settings are excellent examples of collaborative and multi-sectoral efforts that could directly improve the outcomes for individuals and families experiencing possible FASD. Early years programs involve direct on-site participation from health and mental health practitioners who are focused on early identification and interventions to help promote academic achievement and overall success for the students. It is common for the education system to be the first place where problems get identified. FASD informed approaches within these early interventions could lead to more collaborative and complete assessment and diagnostic opportunities.

Although FASD is an indiscriminate disorder, prevalence rates are much higher in regions where a multitude of risk factors are present (Chudley et al., 2005). There is Canadian data that indicates greater prevalence in rural communities, foster care systems, juvenile justice systems and Aboriginal populations. Integrating FASD informed practices into existing programs and services with the education system that are targeting these at-risk populations, would demonstrate improved efficacy and efficiency if FASD informed approaches are adopted (SAMHAS: FASDs Center of Excellence, n.d.; Rasmussen et al., 2012).

Within a policy memorandum regarding community partnerships, the Ministry of Education confirmed that it is "committed to promoting effective community-based partnerships with external agencies that foster continuous improvement in the delivery of programs and services for all students, including students with special needs. Closing achievement gaps for all students continues to be a major priority" (Ministry of Education, 2009 pg. 1). Collaborative and inter-ministerial approaches offering holistic care to the family could begin with the education system more readily through FASD informed identification and intervention programs. Doing so, and nurturing the sense of self in their students, while providing developmentally appropriate programming would help to close the achievement gaps. Effective collaboration between the ministry and municipal boards needs to aspire to high and consistent standards across the province in order to realize the mandate laid out by the Premier.

Ministry of Community and Social Services:

Priorities: Regarding collaborative efforts, efficacy and accountability, Premier Wynne states within her mandate letter to the Honourable Helena Jaczek, the Minister of MCSS, that her ministry is to focus on, "…collaborating with other ministries so that, wherever possible, people using government programs and services can interact seamlessly when a service that your ministry delivers is handed off to another government sector… collaborating with other ministers to align services to provide better support for youth transitions and managing complex needs" (Wynne, 2014). The MCSS has been directed to offer person-centered and cost effective services in collaboration with the Ministry of Health and Long-Term Care, the Ministry of Children and Youth Services, and the Ministry of Education, as required, in order to develop and deliver the second phase of Ontario's Mental Health and Addictions Strategy. The MCSS is to maintain focus on these same objectives, as the MCYS transforms their service delivery for children with special needs and their families.

The MCSS is also directed by Premier Wynne to work towards ending homelessness, to create public policies with other ministries regarding community hubs, and to use public assets, such as government buildings and resources efficiently. Upholding these priorities would also imply stronger ties among community organizations, schools and municipalities.

Gaps and priorities: Research from a variety of sources indicate that some people who are struggling with lifelong poverty, unemployment, school difficulties, and homelessness are struggling because community based supports and services are not able to accommodate their complex needs (Scheimann, 2005). It is understood that people do not often choose to be homeless, or addicted. There are forces at play that are bigger than what we suspect in many cases. Brain damage as a result of PAE, is one such force that is so very often missed (Clarke & Gibbard, 2003; Malbin, 2002). Evidence also indicates that there is a vulnerability among those affected that needs to be understood and supported in a way that alleviates the pressures associated with adult responsibilities and the expectation of independence (Badrey, et al., 2009; Bertrand, 2009; Harriman, 2008). Parents and caregivers express concern about what will happen once they are no longer around or available to support their child/grandchild (Chera, 2010).

By ensuring that this Ministry's programs and services are FASD informed, there is opportunity to begin reducing the likelihood of individuals affected by PAE ending up homeless immediately. It is important to note, for example, that these 'community hubs' could be ideal venues to include services for those affected with PAE. The hubs could also help to provide immediate support for those with complex needs, while providing the coordination required to provide comprehensive assessment and diagnostic services. If individuals have the opportunity to be properly diagnosed and supported, fewer of them will fall outside of the Province's social welfare system (Harriman, 2008). With accurate diagnosis and FASD inclusionary criteria in place, more individuals will qualify for Developmental Services Ontario (including the Ontario Disability Support Program) and will be supported as required, with dignity. As a direct result of FASD informed practices, many individuals will be less likely to end up in bleak and dangerous circumstances.

Ministry of Health and Long Term Care:

Priorities: With regards to collaborative efforts, efficacy, and accountability, Premier Wynne outlines very clearly through her mandate letter that the goal of the Ontario government is to maintain limited expenditure growth. Therefore, the focus of any improvements and growth in health care need to be on enhancing current capacity, by sharing resources and delivering efficient and coordinated care to patients in their communities and closer to home (MHLTC, 2015). Premier Wynne confirmed that the MHLTC needs to continue to work collaboratively with the Minister of Aboriginal Affairs with regards to Aboriginal health and wellness initiatives. Premier Wynne indicated in her mandate letter to the Minister of Health and Long Term Care that this Ministry is also responsible for leading the second phase of the Mental Health and Addictions strategy to support coordinated timely and high quality services. This Ministry has been directed by the Premier to work with the Ministry of Education, the Ministry of Children and Youth Services, the Ministry of Municipal Affairs and Housing in order to develop policy on community hubs to act as venues to deliver health promotion activities. This Minister is also directed to champion the delivery of coordinated care to patients by tapping into the expertise and skill set of all health care providers (Chudley et al., 2005; Hoskins, 2014).

Gaps and priorities: With regards to collaborative efforts, efficacy, and accountability, medical providers who offer primary care are most often the first point of access to our social service system. Families are dependent upon their guidance and direction regarding developmental and well-being concerns, as well as possible interventions that may be helpful (Paton, 2010). Family Doctors, Nurse Practitioners, and pediatricians are the ones primarily responsible for this care and will be the first to see individuals who have been exposed prenatally to alcohol, whether it is known or not. Unfortunately, as iterated within this literature review, there are varying degrees of understanding and awareness regarding the potential devastating effects of PAE; services provided are not as efficient as could be (FASDONE, 2014; Paton, 2010).

There is evidence that prevalence rates for FASD are significantly higher within Aboriginal populations (Comino, et al., 2012). It is vital to understand that the higher prevalence of FASD in these cases is symptomatic of historical and multigenerational trauma, associated with events such as the residential school system. The ‘Sixties Scoop’, which is a term coined to describe the vast number of traumatic and unjustified apprehensions of Aboriginal children from their biological families and having them placed with ‘white’ families who completely refuted the children’s cultural heritage. The goal was to have the Aboriginal population assimilate with the Europeans (Institute of Health Economics Alberta Canada, 2009). Although FASD is not an Aboriginal specific condition, the higher rates cannot be ignored. To do so, and without acknowledgement of the intergenerational trauma which continues to result in higher addiction rates and poorer health outcomes overall, further marginalizes this population. Therefore, screening and addressing possible PAE must include trauma as well as a culturally informed approach (Comino et al., 2012; Larson, 2014; Healthy Child Manitoba, n.d.; Maynard, 2012).

In summary, all Ministries indicate that providing quality and efficient care is critical. Premier Wynne has directed all ministers to be accountable, and it is understood that collaborative planning and direct services provision will lead to optimum care, and will be more cost effective in the longer term. Integrating trauma and FASD informed approaches seem to be quite possible within existing frameworks, and the inclusion of these approaches will lead more directly to the meeting of ministry targets and priorities.

3. Improved mental health assessment and wellness focussed supports and services for individuals and their families.

This third and final overarching priority common among all the ministries reviewed, is that there be a shared, concentrated effort to improve the delivery of mental health assessment and support services, aimed at keeping people well (Wynne, 2014). With regards to FASD, a multi-faceted approach which consider the needs of family members is paramount, because family members have a role to play in directly supporting the individual with FASD in one way or another. In addition to this, family members have their own needs that need to be supported as they themselves are impacted by the demands of this role. A client centered, customized approach to care requires that individuals are properly understood through comprehensive assessment services. Although FASD is not the only cause of neurodevelopmental, mental health and/or behavioural difficulties, oftentimes the role that alcohol may play within the child's presentation is not a consideration (Alberta Health and Wellness, 2007). Additionally, stigma can create barriers to active participation in any assessment process and the accuracy of the diagnosis made. This is magnified in the case of FASD. Because FASD is directly caused by drinking during pregnancy, it is difficult for some women to accept and admit that they are partly responsible for the difficulties that their child is experiencing. Also, parental alcohol misuse and abuse is often monitored by child protection services; therefore, there can be additional fear among parents of ongoing Children's Aid Society (CAS) involvement and possible apprehensions which can also contribute to the reticence to admit to alcohol use during their pregnancies. So, in many cases, instead of considering the potential role of PAE, symptoms are observed and assessed individually, with diagnoses such as ADHD, bi-polar disorder, Conduct Disorder, personality disorders, attachment disorder, or a combination of many disorders more readily made (Guarasci, 2013). These disorders, treated independent of the organic brain damage will prove ineffective in most cases, as demonstrated consistently throughout the literature (Chudley, et al., 2005; Malbin, 2004; Mills, McLenna, & Caza 2006). In order to provide a more comprehensive and client centered approach, the ministries need to look at barriers that people face and therefore consider the determinants of health when planning for any improvements in this area.

Ministry of Children and Youth Services:

Priorities: In her mandate letter to the Honourable Tracy MacCharles, the Minister of MCYS, Premier Wynne indicated that there is a shared goal to promote the mental health and well-being of Ontario's children and youth. The MCYS indicates within its policy framework that the optimal mental health and well-being of children and youth is promoted through enhanced understanding of and the ability to respond to mental health needs (MCYS, 2006). The Ministry's priorities in this area emphasizes the need for early identification strategies to mitigate risks for both individuals and families. In doing so, the MCYS is to work directly with the Minister in charge of the poverty reduction strategy, the Honourable Deb Matthews. Efforts made to address family poverty inevitably promote access to a wider range of services and supports for children with FASD.

Any growth in the mental health system would need to include targeted FASD informed approaches; otherwise the system will continue to have far too many individuals who 'fall out of it'. The Premier has suggested that ministry efforts are to ensure that children and youth have opportunities and hope for their future. In the mandate letter written to the Honourable Tracy MacCharles, Premier Wynne indicated that the MCYS has the responsibility to ensure that children and youth with complex needs are supported. Premier Wynne also directed that efforts in this area are to result in the strategic transformation of Ontario's child welfare system.

Gaps and opportunities: There is a need for FASD to be considered when making improvements to the mental health system because many individuals with undiagnosed FASD present with mental health challenges first, and there are many overlapping characteristics between mental health disorders and FASD (Chera, 2010). The comorbid diagnoses are often treated independent of each other, and with methods that do not work as well for people who have brain damage (Coons, 2013). Failed attempts to improve their circumstances can be very difficult for all family members, as the 'blame' and feelings of parental inadequacy are often perpetuated when suggested strategies from various service providers do not work as expected. Siblings and extended family members are also left puzzled, and frustrated with chaotic familial interactions and increased parental stress as well as time restraints which impact daily living for all. There is opportunity for service providers to be better able to screen and identify those individuals through enhanced early identification programs and services, but additional training will be required for service providers. Immediate and relevant support can be offered following identification with a more targeted effort to have FASD informed practices. We know that we currently do not have the capacity to diagnose all those who meet criteria given the low-estimated prevalence rates. However, with improved screening and identification practices, individuals and families can be better supported while services work collaboratively assessing the necessary domains that will eventually lead to a full FASD assessment.

When children and youth present at a children's mental health agency, their parents are typically referred for parenting support and education that is aimed at addressing behavioural and relational difficulties (Clarke & Gibbard, 2003). It is understood that these programs and services do not readily include FASD assessments and, as a result, the treatments offered are often ineffective and are examples of misdirected human and financial resources (Chudley et al., 2005). Instead, parents benefit from opportunities to learn more about the disorders, to learn about strategies to help to mitigate the problem behaviour, to learn more about what resources their child and family may qualify for, and they also need to focus on self-care and planned respite opportunities (Chera, 2010; Guarasci, 2013; Kotrla & Martin, 2009). There is opportunity to be more intentional with training efforts, which would allow for current service providers to augment their practices and work collaboratively with others in order to provide inclusive supports and services.

The research also indicates that any transformation of the child welfare system needs to include an FASD informed approach since there is a disproportionate number of children exposed to PAE within the child welfare system (FASDONE, 2014). In fact, it is understood that approximately 70% of the children in care have been exposed to PAE (N.O.F.A.S., n.d.). It will be impossible to achieve the above mentioned transformation without considering the FASD population. In terms of family preservation and reducing the number of children and youth in care, it is vital to include the issues for both parents and children who are experiencing FASD, as the level of support and judgement will need to be very different. Parents who have FASD can be wonderful and loving parents, but will need to be supported more intensively than other parents. Although this level of support is not typically offered within existing service delivery, it could be part of the strategic planning for transformed child welfare systems. For children who are misunderstood, there is significant risk of family breakdown, as typical discipline strategies for those experiencing FASD do not work in the same way, and parents and caregivers often inadvertently perpetuate the blame and difficulties for all family members.

Addictions and mental health issues need to be considered, as does the frequency of intergenerational FASD, which further compounds the challenges involved in raising a child with FASD. It is also understood that caregivers are struggling with their day-to-day responses to the behavioural manifestations and caretaking responsibilities and the needs for biological and adoptive/foster families are immense, yet different. In some cases, biological family members are still struggling with substance use issues or FASD themselves, and there is stigma and fear of the social welfare system as a result. In most other cases, biological mothers in particular need to cope with the realization that they are in part responsible for the difficulties that their child(ren) are experiencing due to PAE, and that their best parenting strategies and family circumstances are not enough to ‘cure’ their child(ren). On the other hand, foster and adoptive parents are dealing with the realization that the child(ren) they expected to ‘save’ will continue to struggle regardless of the love, dedication and excellent parenting and family experiences they offer the child(ren). There are many examples of foster and adoptive families feeling ‘duped’ by child protection and adoption workers as the role of PAE has been omitted or minimalized. Therefore, support services for parents and caregivers of children with FASD need to be different as well (Chera, 2010).

Future efforts aimed at improving mental health assessment and wellness supports also need to focus on mitigating the effects of poverty on our children and youth. Policy makers would be prudent to consider instances of intergenerational FASD, and the fact that people who are experiencing real poverty are at much higher risk for other negative life outcomes which include addictions, homelessness, and unemployment (Badry et al., 2009; Comino et al., 2012). Poverty can be a vicious, complex cycle which further compounds the risks for those who have had PAE and possible FASD (Clark et al., 2004; Denys et al., 2009). The research specifies that poverty reduction strategies need to be customized accordingly (Harriman, 2008). Supportive and holistic (all-inclusive, considering the determinants of health) supports that are well case managed - rather than punitive approaches - are what will help improve the mental health functioning of all family members experiencing FASD (Adnams, et al., 2007; Denys, Hennevald & Rasmussen, 2009; Harriman, 2008). Without seeing families through this FASD and complex neurodevelopmental disorder lens, services will continue to fail these individuals and families will often fall apart (Bertrand, 2009; Breen & Burne, 2012; Burns et al., 2013; Graefe, 1999).

The children’s mental health system is currently taxed with long wait lists and significant need (Chera, 2010). The research clearly demonstrates that trying to provide mental health supports and services to an individual with unrecognized brain damage simply does not produce the desired results. As a result, the system will never experience the kind of success that it is working so diligently to achieve without targeting FASD and having those exposed prenatally to alcohol properly screened and assessed. Parents are in need of support and education and the system also needs to address the complex needs associated with PAE more directly, with efficacy in order to see the gains hoped for in the area of family support.

Ministry of Education:

Priorities: Regarding efforts to improve mental health assessment and support services, this Ministry has been directed by Premier Wynne through her mandate letter to focus on the promotion of well-being for students. Minister Liz Sandals has also been directed to ensure that all students have the opportunity to enhance their mental and physical health, in a school climate that nurtures the development of a positive sense of self and belonging. The Premier, in her mandate letter to the Minister of Education, prioritized the inclusion of child care and early year's programs and services within the educational system. The implicit goal is to improve the experiences for young children through 'one stop shopping' for services through Best Start Child and Family Centers within elementary schools. The plan involves full day kindergarten being offered to all students, and this ministry is to work directly with Minister of Tourism, Culture and Sport in order to offer quality before and after school programming for children 6-12 years, through the school boards themselves or through a private third party.

Advice offered to the Minister of Children and Youth Services from the Honourable Tracy MacCharles in 2013 included areas within the education system that needed to be improved. Using a "wait and see approach" in the early years programming when developmental problems have been identified, is an area that families would like to see improved. The Honourable Tracy MacCharles also commented on the need for school staff to be offered specific training and coaching with regards to educating and supporting children with special needs in an inclusionary manner. The Ministry has set out to increase levels of student achievement with the goal being to have an 85% high school graduation rate (Achieving Excellence, 2014). The Premier also has agreed that academic requirements are more easily realized when the individual's spirit and sense of self has been nurtured (Malbin, 2002; Wynne, 2014).

Gaps and opportunities: Early years programs and services offered within community schools would provide ideal circumstances to implement comprehensive developmental screens that would help to identify FASD, and to be able to start with relevant supports earlier for these children and families (Goh, 2005). After school programming to include children older than 12 but who are in need of structure and supervision would be of benefit for families affected by FASD (Breen & Burns, 2012; Chera, 2010). These early screens can immediately involve invitations and encouragement for parents and families to access supports and parenting programs that include FASD informed approaches, to increase parenting capacity and to improve resiliency for all family members.

Undoubtedly, it is difficult to positively nurture one's spirit and sense of self while feeling misunderstood, having been misdiagnosed, and consistently experiencing difficulties meeting day-to-day expectations within the school environment (Bredberg, 2011; Dybdahl & Ryan, 2009; Skerrit, 2008). Increasing student achievement and graduation rates will be more attainable if those with PAE are more appropriately understood and supported. Augmenting existing special education efforts to include FASD informed practices will help this government to realize the goals that it has set out for the Ministry of Education.

Ministry of Community and Social Services:

Priorities: In terms of improving mental health assessment and wellness focussed supports and services, the MCSS has been asked to provide services that would support these areas of need for those with complex disabilities (Wynne, 2014). The Minister of MCSS has been tasked with providing supports and services such as semi-independent living arrangements and employment and educational opportunities that promote reasonable independence.

Gaps and opportunities: It is important to be reminded that individuals with FASD are often less visible in terms of 'disabilities'. Their scattered and complex profiles often do not always lend themselves well to existing supportive housing/residential programs, for example (Chera, 2010; Harriman, 2008: Healthy Child Manitoba, n.d.). In fact, the environments that are best suited to address either significant mental health issues or developmental disorders, independent of one another, can in fact be more detrimental than good for the youth with FASD because they don't really believe that they 'fit' with either condition (Chera, 2010). What is also detrimental, however, is the more common practice of offering incomplete assessments and determining that individuals are more capable than they actually are (FASDONE, 2014; Guarasci, 2013; Harriman;).

Research evidence indicates that individuals with PAE benefit from coaching, mentoring, interdependent relationships, identifying their strengths, and having opportunities to nurture them in order to enjoy more success in daily activities (Graefe, 1999: Harriman, 2008). There are opportunities now to include FASD informed approaches, within existing service delivery, which would enable more opportunities for supported living arrangements and intensive community case management services to better address the complex needs.

Ministry of Attorney General:

Priorities: In terms of improving mental health assessment and wellness focused supports and services, Minister Madeleine Meilleur has been asked to reform the family law system to include better responses to those who require extra support (ie. Domestic violence, mental health and other concerns). The Minister of the Attorney General has also been directed to strengthen the relationship between Aboriginal Peoples and the justice system (Wynne, 2014).

Gaps and opportunities: All areas of family and criminal law would be better positioned to offer relevant support if their services were offered through an FASD lens. For example, if parents who have been affected by PAE were better understood and supported there would be fewer traumatic apprehensions and custody battles with child protection services (Harriman, 2008; Larson, Brassard, Sink, & Cowen, 2014). The majority of children who are born with FASD do not live with their biological families; therefore, child protection services and family law are involved (Popova, Lange, Burd, Rehm, 2013). The argument for enhanced understanding of the impact of PAE within family law is a good one, because family preservation is a priority for child protection interventions. Mothers who have FASD themselves are often very loving and capable parents with the right supports in place. There has been much promise demonstrated in community based groups and interventions that include case management, mentoring and more direct and frequent involvement from service providers. Scheduling assistance, reminder calls, transportation, life skills training, vocational planning and friendly home visits are all things that prove to be helpful in keeping families together and out of the family court system (Denys, Rasmussen & Henneveld, 2009). Adoption and foster parent breakdowns will also be reduced, if children with FASD are better understood and supported while parents are offered the support and respite that they need in order to be as strong and as healthy as they can be (Rasmussen, et al., 2012)

In terms of youth justice, currently, section 34 assessments are ordered for youth whose mental status is being questioned before sentencing takes place. An FASD informed practice would help to ensure that these assessments are looking beyond mental health, personality issues and standard risk assessments. At this time, however, there are few forensic psychological assessment teams adequately funded or prepared to include the types of measures that would determine if the youth is experiencing FASD or a complex neurodevelopmental disorder (FASDONE, 2014). There is a need to build clinician capacity in this area as well, as indicated within a research report from the CanFASD research network, and there need to be policies and/or standards of practice that consider the high prevalence rates and the likelihood of PAE being a factor. “There is a need for enhanced understanding of the concerns of people living with FASD in all of these areas; e.g., victims of crime; as witnesses; as individuals in conflict with the law; and in family, and civil matters) of the justice system” (Cook, Green, Salmom & Stewart, n.d. p.1).

Recognizing the higher prevalence rates among both Aboriginal communities and the justice system magnifies the necessity within Premier Wynne’s directive to this Minister to target diagnostic services in order to keep PAE affected youth out of our justice system, and instead better understood and supported. Efforts made to keep Aboriginals out of the justice system would be difficult to achieve without being mindful and intentional about the high prevalence rates of PAE. Currently assessment for FASD is not typically pursued in many areas within the province of Ontario, and as mentioned, even in areas where assessment services are available, and service providers are aware of FASD, the demand far outweighs the capacity.

Ministry of Health and Long Term Care:

Priorities: In terms of improving mental health assessment and wellness focussed supports and services the MHLTC has also been directed by Premier Wynne to continue to focus on keeping people healthy with evidence based education and prevention strategies that take place at a community level.

The MHLTC in Ontario has expressed its promise to improve the health and wellbeing of all of its constituents, and it has been tasked to lead the second phase of the Mental Health and Addictions strategy, to support improvements in timely access to coordinated and quality services (Hoskins, 2015).

Gaps and opportunities: There is opportunity to discover options as to how best to deliver complex prevention, assessment and support interventions, being inclusive of FASD specific issues. Currently, there is indication of some resistance to screening for FASD at the primary care level partly due to lack of available support services, as well as comfort level delving into more personal issues such as drinking habits, for example (Alberta Health and Wellness, 2007: Chera, 2010; Goh, 2005). As a result, many individuals go on to be misinterpreted and very often misdiagnosed. Offering quality primary care involves comprehensive assessments regardless of comfort level; therefore, there is opportunity to re-evaluate the accountability and the responsibilities of the practitioners in this regard. Opportunities to offer improved multi-disciplinary and holistic care could help ease some of this discomfort on the part of physicians, and put the screening responsibility for complex cases in the hands of the team member who has established a therapeutic alliance with the individual and family. Community based multi-disciplinary primary health care teams offer the kind of service delivery that could easily integrate FASD informed practices in order to offer improved mental health and wellness focused initiatives across the lifespan in the areas of prevention, diagnosis and interventions. Research evidence confirms that there is significant cross-over between mental health diagnosis and addictions with people who have had PAE (Stade et al., 2009; Thanh et al., 2013). Therefore, it would be prudent to implement an addictions and mental health strategy with the understanding that a significant number of their patients will have been negatively impacted by PAE (Coons, 2013; Denys et al., 2009). The evidence undoubtedly indicates that treatment and supports for people with FASD need to be considerably different than for those with strictly mental health and addiction issues (Rasmussen, et al., 2012). There also are varying degrees of comfort level when addressing the complex needs of those individuals with PAE and addiction issues, so service providers are not doing all that can be done in terms of prevention efforts, harm reduction, and supports and services for the real issues behind the behavioural, social and cognitive difficulties that present (Alberta Health and Wellness, 2008; SAMHAS: FASDs Center of Excellence, 2007).

Hospital based mental health programs including crises and emergency care see those affected with PAE very regularly, but once again, most often these patients are being assessed based on their behavioural and emotional presentation which is not sufficient (Caza, McLenna, & Mills, 2006). FASD informed practices within hospital settings will contribute to the improvements in mental health and wellness focused supports and services that the ministry is aiming for. If FASD continues to be excluded from hospital based medical and mental health services, individuals are more likely to find themselves in difficult circumstances, which result in overuse of costly crisis medical services (FASDONE, 2014). This Ministry seems committed to exploring options for providing the right care to all Ontarians in the right place at and at the right time, but clearly without an appropriate diagnosis, and without efforts aimed at prevention and mitigating risk factors, improvement in mental health and wellness focused supports and services is not possible (FASDONE, 2014).

In summary, all Ministries believe that improvements in the area of mental health services are needed. Research findings indicate that these desired outcomes will not be realized without considering that up to approximately 50% of their existing clients may, in fact, be struggling as a result of PAE (Bell, & Chimata, 2015). This comprehensive review of the literature demonstrates that the Ministries have mandates that require them to target the needs of the FASD population and work collaboratively to improve access to assessment and support services. In order to do so with efficiency and efficacy, the literature review has demonstrated that there needs to be an increased ability on the part of service providers to recognize the effects of PAE and be better positioned to offer supports and interventions that will lead to more positive outcomes for individuals and families at each point of social service system entry.

Chapter five: Discussion

The findings from this research project have highlighted, first and foremost, that there is tremendous need for social welfare services in Ontario to be more inclusive of the needs of those experiencing FASD. Secondly, the findings have demonstrated that FASD is largely an invisible disability and there is a lack of understanding in terms of prevalence rates, the impact of PAE, what FASD really looks like in terms of behavioural and emotional manifestations, and what support individuals and family members desperately need. There is also an absence of understanding that supporting those with FASD falls inside all job descriptions within provincially funded services. Thirdly, the research verifies that all the ministries reviewed for this project all have a mandate to ensure that all individuals have access to assessment and diagnostic services as well as evidence informed support services. In fact however, findings have demonstrated that without FASD being directly documented within strategic plans, few service agencies and educators currently have the resources and confidence to address the issues with competence.

The goal of this project was to determine opportunities to improve the circumstances for those affected by PAE. The research question was as follows:

Given the state of current FASD research and political realities that influence program development in the treatment of individuals with FASD impairments, this thesis asks what may an optimal model for FASD assessment and support/interventions entail.

In order to realize required gains in the areas mentioned above, strong leadership will be critical moving forward. Resources in the form of staffing and dollars will need to be designated, based on population and geography, in order to implement and evaluate provincial, regional, and local capacity building efforts. The following activities and strategies are suggested.

Recommendations to improve circumstances for those affected by FASD:

1. Cross-sectoral collaboration to ensure a shared responsibility, as well as a commitment to system capacity building and the integration of FASD into existing social welfare infrastructures.
2. Accredited social welfare service agencies to develop policies for an FASD informed approach to service delivery.
3. Training and education opportunities with strategic schedules aimed to improve service delivery at points of entry while supporting ongoing prevention efforts.

Strategies to operationalize the above mentioned recommendations are as follows:

Cross-sectoral collaboration to ensure a shared responsibility, as well as a commitment to system capacity building and the integration of FASD into existing social welfare infrastructures: FASD needs to find a 'home' and because this disorder crosses over so many ministries and mandates, it is recommended that a government mandated and supported inter-ministerial leadership group be formed, with Parliamentary Assistants' participation from the five ministries examined within this report. In terms of prevention efforts, it would be sensible to include the Ministry of Health Promotion and Sport representatives at this table as well. It is recommended that this group also include representatives from: FASD consumer or caregiver groups; researchers; FASD informed clinicians; representatives from FASD Ontario Network of Experts (ONE), as well as indigenous populations. In order to facilitate this group, and to ensure active participation and accountability, it is recommended that a non-partisan provincial FASD ombudsman position be created. This position will be able to guide the leadership table with current global research as well as family experiences. A government mandated and supported provincial inter-ministerial coalition working collaboratively is required in order to ensure fair and equitable access to supports and services regardless of where people live in Ontario. Obviously, geographical considerations need to be made, but with access to telehealth, services are more readily available to even the most remote areas. Currently access to FASD services is reliant upon the expertise and desire within communities as well as access to charitable donations. FASD is a preventable disorder; therefore, investment in this area will produce significant dividends in terms of emotional and fiscal realities.

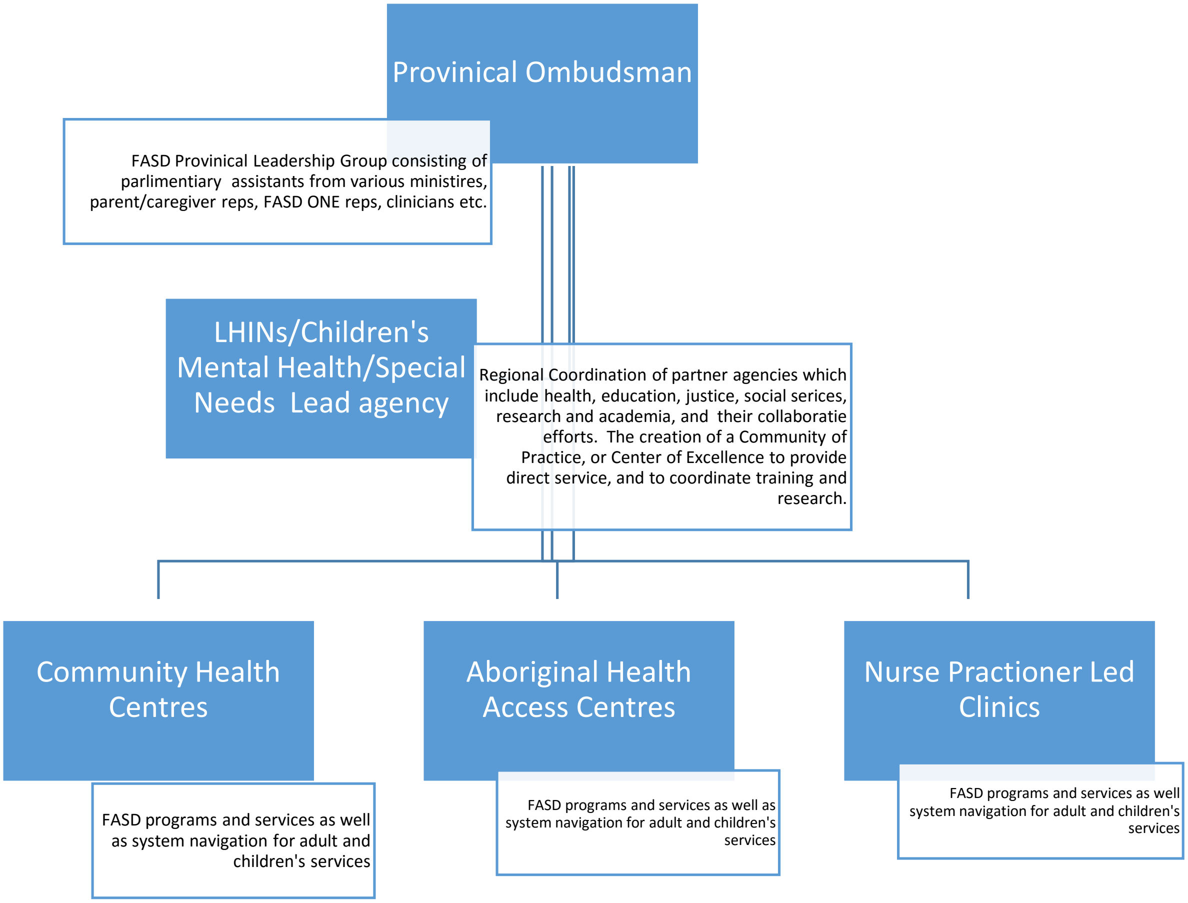
Government will need to make a financial commitment to this initiative as managed by this cross-sectoral ministry leadership group, recognizing that the investment priorities will shift weight over time from an emphasis on training, prevention, and broad system capacity building to ongoing research and promising treatment and support services. It is important to acknowledge that the targeted investment will result in fewer misdirected services and fewer examples of inefficient use of resources. Appendix C, demonstrates the high cost of misdiagnoses to the mental health care system. Overtime, one would anticipate a decreased need for targeted FASD services. According to the research, Ontario is quite far behind in terms of an inter-ministerial provincial strategy and there is much to be learned from other Canadian provinces and in some areas across the globe. For example, British Columbia began to focus efforts towards improving the circumstances for those affected by PAE with a province-wide strategy in 2003. The province of British Columbia has a population of 4.63 million, and currently invests ten million dollars through an inter-ministerial committee. Ontario’s population is about three times greater at 13.68 million; therefore a comparable investment would be in the neighbourhood of 31 million dollars. Table 3 provides a synopsis of the provincial commitments and strategies to date, across Canada.

It is very promising to see that the MCYS is beginning to consult with stakeholders and communities in order to see how to develop and implement a provincial approach to FASD services. So far, in Ontario, targeted efforts have been more frequently focussed on identifying and supporting children and youth who have had PAE. However, given that there are more adults than children in the general population, we can deduce that there are more adults than children who may require an FASD assessment; therefore, collaborative effort among ministries that includes adult services is required. In terms of adults experiencing FASD, it is recognized that current eligibility criteria for ODSP and DSO services, for example, is inclusive of FASD; however, due to lack of awareness and accessible diagnostic services, many adults fall through these cracks and end up without any, let alone appropriate support services. For example, with regards to community based supports, the Canadian Mental Health Association is an agency that offers case management services for individuals struggling with severe and chronic mental illness; many of whom have also had PAE, but are unaware. In some cases, the heightened FASD awareness would simply allow for FASD to be integrated into existing services including reminder calls, transportation arrangements, intensive safety plans, tools to support memory and follow through, advocacy and training for community supports (formal and informal), that can provide a strength-based circle of support around the individual. Sadly, most of these individuals are not currently acknowledged to be in need of case management services. If they are identified with challenges, they are most likely to be supported by virtue of mental health and behavioural issues, without the consideration given to the organic brain damage that resulted in cognitive and daily living skill deficits. Simply by being better understood, and by nurturing inter-dependent relationships, individuals with FASD will be happier individuals who are better positioned to engage in positive life experiences.

The provincial cross-sectoral leadership group will oversee services based on research and expertise, guide policy development, and provide core funding for the commitments at regional and community levels. Regional coordinators and FASD Communities of Practice or Centres of Excellence are recommended within existing children's mental health and treatment centres. FASD diagnosticians would be available with core funded services, to enable the completion of a pre-determined number of assessment clinics each month. The Regional Centres of Excellence or Communities of Practice would also be tasked to ensure that there is consistency in terms of service delivery and it would also allow for ongoing training and consultation within the region as needed.

Ideally, at the local level, core funded FASD coordinators would mobilize the community to ensure that families are well supported through FASD informed practices, and that assessments are coordinated locally by community based service providers where possible. The Association of Ontario Health Centres is well positioned to lead such initiatives at a community level through the existence of community primary care agencies, which include Community Health Centres, Aboriginal Health Access Centres, and Nurse Practitioner led clinics. These agencies are mandated to provide holistic primary health and mental health care across the lifespan to marginalized populations. Their focus is on the determinants of health and health promotion, through education and early identification and prevention strategies. Their target populations include those who are at higher risk of being negatively impacted by PAE. They also have mandates which include promises to reduce health care costs through prevention efforts and holistic care; therefore these agencies seem to be an ideal fit to lead efforts at a community level for the needs of those experiencing FASD.

Figure 2, Flow Chart of a model that could be a template for service delivery across Ontario.



FASD Provinical Leadership Group consisting of parlimentiary assistants from various ministires, parent/caregiver reps, FASD ONE reps, clinicians etc.

Regional Coordination of partner agencies which include health, education, justice, social serices, research and academia, and their collaboratie efforts. The creation of a Community of Practice, or Center of Excellence to provide direct service, and to coordinate training and research.

FASD programs and services as well as system navigation for adult and children's services

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FASD programs and services as well system navigation for adult and children's services

Accredited social welfare service agencies to develop policy for an FASD informed approach to service delivery: It is recommended that the provincial government insist that all publicly funded and/or accredited agencies within health, education and social services have policies developed that ensure that they are FASD informed and are able to offer, contribute to, or coordinate comprehensive, holistic, multi-disciplinary FASD assessment, support services and health care at the point of service entry and beyond. While this is contemplated by government, and/or under development, it is recommended that community coalitions insist that membership involves a signed protocol agreement that indicates that they are going to be intentionally inclusive of FASD in their service delivery. This is going to entail that the agencies commit to providing resources to ensure that everyone in the agency is offered training specific to their scope of practice. An example of priorities and strategies to be included in policy would be as follows:

1. Treatment for FASD must be strength-based, and address the neurodevelopmental deficits such as memory and language impairments.
2. Reminder calls are helpful as memory and/or executive function problems may make it difficult for clients to remember to attend appointments. Coordination of same day appointments is helpful, often with transportation pre-arranged by a system navigator or case manager who is able to attend as well.
3. Support services must continue even when progress has been made. The progress is a result of the inter-dependent relationship, and the individual with FASD is at a much higher risk of reverting back to previous behaviours without ongoing long-term supports and services.
4. Family support and planned respite is an important part of treatment and support services as the needs of caregivers are high in terms of self-care and family preservation.
5. Having the parent/caregiver directly involved in the treatment planning for the individual who has had PAE is essential in order to assist with follow through and the

establishment of inter-disciplinary relationships that can provide a circle of support to the individual for the long term.

6. Sensory integration problems are common with individuals with FASD and often manifest in maladaptive behaviours. Individuals with FASD should be connected to an Occupational Therapist in order to further understand this sensory and adaptive functioning capacity and to provide appropriate treatment. These sensitivities are seldom acknowledged for what they actually are, and they can have profound impact on mental health and addictions treatment. The continual feeling of being uncomfortable makes individuals more susceptible to substance misuse in the attempt to numb the discomfort. These sensitivities, are commonly overlooked, and impede traditional treatment approaches.

Without directives to include FASD within existing employee responsibilities, this research project has indicated that most human service professionals will not understand the need, or their own capacity to shift and augment their practice in order to be inclusive of the needs of those affected by PAE. Most people in helping professions already have full caseloads and exhausting demands. The mere idea of learning something new or taking on further responsibilities is often a barrier, especially before it is clear to the individual that we're already doing the work; those affected by FASD are on our existing caseloads. Unfortunately we're just not doing it effectively and consequently, are becoming increasingly frustrated when we are not experiencing the kind of success with individuals and families that we feel we should be.

FASD is a spectrum of disorders, and recognition of the possibility of PAE being a contributing factor will happen at different times and at different places. We may see individuals enter the system with inquiries about what could be neurodevelopmental deficits at family doctors' offices early on; within early years programming; within the school system; within the child welfare system; within the children's mental health system; within the hospital emergency departments; within adult mental health agencies; homeless shelters; developmental services; and justice departments. Therefore, with FASD informed practices, and improved universal screening and intake processes, our system could begin immediately to identify and formally assess individuals who present with what could be complex neurodevelopmental disorders and work towards a diagnosis if required.

The inclusion of FASD within community agencies or schools should be formalized with internal policies that ensure that there is a dedicated FASD lead or expert could be responsible to facilitate individual education plans and appropriate referrals for the individual and family. For example, if a child is identified within the school system at a young age experiencing developmental and behavioural challenges, referrals can be made through existing school mechanisms (current referral processes for students identified with behavioural problems and/or mental health needs) to ensure that FASD informed evaluations begin. School board psychology, and speech and language services can begin to be delivered through an FASD lens, as could occupational therapy, to determine the subtle needs that may be present with a child who has had PAE. Most often, families would also be referred to community based mental health agencies for treatment and support services where they could access augmented psychological testing and receive consultation and case management services. Partnerships with medical providers such as Association of Ontario Health Centres (AOHC) member agencies, for example, would allow for the completion of the FASD assessments and the provision of holistic and ongoing community based supports for those families with high need. An example of this would be the Nurse Practitioner led clinic that operates within a MCYS funded community mental health agency in London, ON. The Family Support and Crisis Centre provides crises support and respite services for high risk families, many of which have had PAE. Therefore, an FASD informed medical practice on site would provide optimum medical care while participating directly in FASD assessment services, as well as concurrent prevention and support programs. Relationships are so important when dealing with marginalized and vulnerable populations, and the opportunity to nurture those relationships helps to reduce barriers to health care services. If, however, the child is already connected to a pediatrician, then this practitioner could also be trained in the Canadian Guidelines for FASD diagnosis and offer their contribution to the multi-disciplinary team FASD assessment team.

If a child or youth is presenting with more urgent mental health needs and is presenting at the local emergency department, or hospital based mental health services, then policies would ensure that FASD screening and assessment is a dimension of the core diagnostic services provided. The research suggests that that it could make most sense to facilitate a diagnosis within the mental health department at this hospital setting, utilizing existing FASD informed service providers. Families are indicating that they do not appreciate telling their story multiple times and when patients present in an emergency department, there is implied desperation, which requires that the level of urgency needs to be thoroughly understood in order to avoid sending the individual home with insufficient supports and strategies. If more time is taken to screen properly for FASD, or a complex neurodevelopmental disorder, it is true that more resources will be needed at the front end to ensure proper assessment services. However, this investment will be well worth it in the end when the individual and family can begin seeing the complex needs more clearly and consequently customize the strategies to be more in line with developmental needs rather than on the behavioural presentation, and suspected mental health needs.

If a young person presents with urgent mental health needs at a tertiary mental health facility such as the Child Parent Resource Institute (CPRI) in London ON, then internal policies would guide practices to ensure that the family is connected to an FASD Coordinator or Special Needs System Navigator with FASD expertise that will facilitate assessment and support services. It would make most sense on a number of different levels to offer FASD assessment services within their existing programming. CPRI offers diagnostic services for Autism Spectrum Disorder and, according to their website, virtually all other developmental and mental health conditions; therefore, it would seem plausible that FASD be included in their services and that their clinicians all become FASD informed in order to do so adequately.

When a youth presents within the justice system and mental health and developmental concerns are raised, the courts can order a Section 34, Forensic Psychological assessment in order to determine most appropriate sentencing options and treatment recommendations. As indicated previously in this report, the courts can order a section 34 assessment to specifically investigate FASD. Internal policies should ensure that developmental screens are completed with all clients and that these assessments are the starting point for all those with positive screens. Arson prevention and personality measures have very little value if it is determined that the individual has FASD because the validity of the measures is often in question. In addition, a perceived lack of empathy, for example, could instead be a genuine lack of understanding of impact and/or memory of the events that became problematic for others. Improved supervision based on neurodevelopmental dysmaturity would be a recommendation within an FASD assessment which would take care of any fire related concerns. Consequently, there could be a significant fiscal and emotional cost reduction if provided. The prevalence rate of PAE within the justice system is understood to be disproportionately high. Therefore, the research suggests that training and capacity building efforts targeting court and justice employees, as well as assessment teams across the province, to ensure that all are familiar and utilizing the Canadian Guidelines for FASD diagnosis is necessary and would enable our justice system to more completely assess and support those youth with complex neurodevelopmental disorders.

It is recommended that a designated local FASD Coordinator, possibly housed at a local community based primary health care facility such as an Association of Ontario Health Centres member agency – a Community Health Centre, Aboriginal Health Access Centre, Nurse Practitioner Led Clinic), would be available to support diagnosis, consultation and support as required. This coordinator would also assist the family with system navigation, and would also gather and keep statistics that will contribute to further program evaluation and research.

Consistent policy to ensure FASD informed practice is offered at all points of entry will mean that people in need would be identified earlier than they are currently. This earlier identification will mean that services can be streamlined and coordinated in a way that better addresses the complex invisible disability. This will most likely lead to better outcomes immediately, and reduce the risk of secondary disabilities. See appendix D, for diagrams of care paths for individuals who enter the social welfare system at various points.

As we continue to build capacity, within a few years all service providers will be better able to recognize, refer appropriately for assessment services, and support individuals with PAE. This cannot be done without policy makers and leadership teams including these priorities within their strategic plans and a commitment of resources to make the service accessible through all of these different points of entry.

Training and education opportunities with strategic schedules aimed to improve service delivery at points of entry while supporting ongoing prevention efforts: Once policies are in place to ensure an FASD informed practice, strategic training schedules need to be developed and implemented to ensure that these polices can be realized. The first priority in terms of training and education must target current service providers as they most immediately need to augment their practice and be better able to screen, recognize, support and refer families for appropriate services. Improvements to the social welfare system will not be realized without this training and the inclusion of FASD within supports and services. It is recommended that professional colleges and associations be directed to include FASD competency training as a requirement for ongoing professional development; and this training would be facilitated through the expertise found within the provincial inter-ministerial leadership group and /or affiliated working groups.

In terms of awareness and prevention efforts, FASD needs to be incorporated into courses within our elementary and secondary school systems. Years ago, children were coming home from school informing their parents of the risks and dangers of smoking. This same effort can easily be made to increase the general public's understanding of the risk factors associated with alcohol beyond FASD. Additionally, all post-secondary students should receive targeted and universal information as part of the orientation process as we know that there are higher rates of alcohol use and unplanned pregnancies for this age group. FASD certification programs would be beneficial as well; however, more importantly, all post-secondary students training in human services and health care should have mandatory curriculum as a part of their graduation requirements, to ensure that new graduates are better able to recognize, refer and support individuals with PAE and /or suspected complex neurodevelopmental disorders.

In summary, training and professional development will immediately lead to services that are more appropriately addressing the needs of individuals and families. For example, if a child is accessing respite services at a community agency, the child can be immediately screened by FASD informed service providers allowing for more realistic expectations to be placed on the child. Additionally, simple environmental accommodations can be made in order to mitigate risk and promote successful experiences. The point to be understood here is that this family requires respite and will be offered it within this agency regardless. The respite experience, however, will be beneficial for all if this child's needs are better identified and understood. If, on the other hand, this child is understood to have behaviour problems which result solely from choice and poor parenting, this respite service will be counterproductive, and in fact perpetuate existing problems for the individual, family and staffing team. More intensive FASD training needs also to be provided for clinicians who are interested in developing expertise and specialization for complex diagnostic services and to contribute to ongoing and ever emerging research initiatives. The expected long term outcomes of this strategy are as follows:

1. There will be fewer incidents of alcohol exposed babies and FASD, and therefore less need for assessment, and support services.
2. FASD informed service providers will be immediately available with clear referral, intake, assessment and care plans established from the outset.
3. Increased confidence in service providers able to include FASD within their scope of practice
4. Individuals and families will be better understood and supported resulting in fewer kids in care, fewer youth in the justice system, fewer homeless adults, fewer subsequent alcohol exposed pregnancies, and increased number of school graduates, and supported vocational experiences.

Table 5 provides a logic model describing a community development approach to FASD programs and services that relies on cross-ministerial collaboration as well as individual and system capacity building efforts.

Table 5 FASD informed practice – A Logic Model

Inputs and Goals	Activities	Strategies and short term results	Outcomes	Long Term Outcomes
Government commitment to provide resources to fund a provincial advocate and FASD expert	Hiring of an FASD ombudsman	Ombudsman hired to oversee and lead provincial cross-sectoral leadership group. Ombudsman is accountable to ensure that all ministries and groups are represented.	Initiatives are guided by research, family experiences and best practices. Sustainability of Cross sectoral group is possible with non-partisan leadership.	
Parliamentary assistants for various ministries, parent reps, FASD ONE reps, clinicians, researchers join a cross sectoral leadership group	Strategic plans developed with goals, strategies and financial investment clearly established. Confirm coalition membership and development of policies	Funding and expertise provided to establish FASD Communities of practice or Centres of Excellence.	FASD resources and expertise available to establish sustainable programs and services and train the trainer opportunities Funding is determined and disseminated	
Financial resources for administrative support and electronic record keeping	Establish coordinated and integrated intake and data collection mechanisms	Improved efficiency and streamlined communication between assessment team members and circle of care	Mitigating duplication of files; recognition of FASD as a core and specialized service area and improved tracking and ability to plan and evaluate	
Financial resources to establish FASD/Complex Neurodevelopmental Disorders (CND) collaborative Financial resources for FASD/CND community of practice or Centre of Excellence Program coordination	Facilitate ongoing training for front line and emerging clinicians and facilitate individual and family supports	Active regional coalition with established protocols and signed agreements FASD/CND informed service providers who can contribute to prevention, assessment and supports	Increased FASD awareness within participating agencies, community partnerships working on capacity building efforts and FASD/CND informed services Increased # of assessments complete; improved individual/family circumstances with improved access to services at point of system entry	
Financial resources to provide clinical assessments. (Psychological assessments are the most time consuming and costly of the multi-disciplinary FASD assessment process, and are seldom fully funded. If they are funded, there is typically a long wait list, therefore resources are necessary as an investment to build clinician capacity.)	Clinical assessment services for FASD/CND referrals	Train the trainer and consultation services in increase clinician and overall system capacity	Increased clinician expertise and confidence level with more clinicians able to participate in FASD/CND assessments. FASD Centre of Excellence able to offer 4 assessments per clinic day 4 times a month for complex individuals. (Clinics offered will be open to having other clinicians join as part of the training and capacity building initiatives)	Fewer incident of babies with PAE, shorter wait lists, fewer secondary disabilities and adverse family circumstances, and FASD/CND informed health, education, and social welfare services; significant cost savings for all ministries and most importantly, the individuals and families experiencing FASD/CND

Implications for social work practice

The research indicates clearly that FASD crosses over many different ministries, all of which require targeted policy development to ensure inclusion of FASD as well as other complex neurodevelopmental disorders where the cause is unknown. Our service system needs to change and we need social workers to continue to advocate and lead in this system transformation. In terms of service provision, services should be relatively local, with attempts made to reduce barriers to services including transportation, poverty, isolation, and child care. In order to address the complex needs of families experiencing suspected FASD, flexible scheduling and services are often necessary. Community based programs and services commonly delivered by Social Workers can creatively tackle problems at a broader level through prevention strategies and the inclusion of informal supports (Burgoyne, 2006). Some of these informal supports would include family members if available, peer support, self-help groups and informal networks that become nurtured and more intentionally developed and sustained. This type of ‘intimate’ interaction over the long term holds much promise when delivering services to high risk families and these too are often initiated and/or delivered by Social Workers (Rasmussen et al., 2012). The issues that present themselves within families living with FASD are unpredictable and very complex. They do not always occur during regular ‘business’ hours, therefore natural and flexible supports that stay with the family over the long term seem to hold much promise for struggling families (Michaud & Temple, 2013). Social Workers can help establish these kinds of linkages by offering meeting space, training, and ongoing support.

As a result of varied family needs, Social Workers will need to be prepared to deliver programs that are long-term, voluntary and enjoyable for individuals and families who are at risk of making unhealthy and /or misinformed decisions, i.e. unplanned pregnancies, unhealthy relationships, alcohol and drug use and misuse etc. (Denys et al., 2009). Customized programs and services need to consider the support required for individuals to stay focused on vocational and academic goals and other life domains that help to determine the overall health outcomes for people (Brown & Hannis, 2013; Rasmussen et al., 2012)

The social work profession is directly responsible for providing support to vulnerable populations and contributing directly to policy change. Ongoing social work participation and leadership within the proposed cross-sectoral working groups will be beneficial moving forward. Social workers will need to continue to advocate for long-term, focused programming and system navigation to be provided within an agencies that are FASD informed. This approach is most likely to lead to improved short and long term outcomes for the participants, and it will require social workers to continue to work to ensure that this system change is prioritized within government mandates and human service agencies.

It is recognized that there is very little research completed in the area of specific treatment and support interventions for FASD, but there is enough to begin planning, developing and implementing evidence informed programming which is most likely to yield positive results. It is also understood that a diagnosis coupled with opportunities to educate and support the parents with FASD specific strategies has the potential to be of tremendous benefit to all family members.

Research indicates that parents with FASD have the same hopes and dreams that we all do, for themselves and more specifically for their children (Michaud & Temple, 2013). There is a fear of ‘the system’ in many cases and the reasons for this are varied and complex. In addition to this, there is reluctance to get help for secondary disabilities for fear of it being used as ‘evidence’ of their incapability to parent effectively. Often there is a fear among parents that they will be diagnosed themselves with FASD (Denys et al., 2009). As social workers, helping to understand the needs as being beyond behaviour and assumed inadequate parenting will help to reduce stigma and blame and begin to help strengthen families and help individuals reach their potential. Facilitating the training required in order to deliver FASD supports and services can and should be offered by social workers as we have the opportunity to continually hear directly from individuals and families whose lives are affected.

Limitations of the Study

FASD assessment and diagnostic capacity is slowly but continually building. It is virtually impossible to feel that an integrative review of the literature is ever really complete. Every day there seems to be some progress made and/or another horror story shared by families who are experiencing atrocious challenges due to an ill-informed and unprepared service delivery system. Research strategies typically involve literature searches, but diagnostic clinics and models of service are so new that it was difficult to know whether all of them have been included. Provincial and state networks were tapped into for this study, but it is understood that not all assessment and diagnostic opportunities are formally documented and accounted for.

Future research

Although FASD is not a new phenomenon, in terms of service delivery, in Ontario we are, in fact, in our infancy stage. Thus, there is plenty of ongoing research that would be helpful in this area. We can continue to evaluate current assessment clinics and support services as they expand and become more community based to see if individuals and families are doing better as a result of the diagnosis and support services. Evaluation of the proposed capacity building efforts and the involvement of multi-disciplinary community based primary health care teams will be necessary as well to determine the feasibility and effectiveness of community based models. We suspect that they will be, but FASD programs and services will require ongoing monitoring and evaluation to ensure that continuous improvements are being made. There is also a need for research in therapies and treatment modalities that will improve cognitive functioning, social inclusion and overall outcomes for those with an FASD diagnosis. Additional research as to how best to support families experiencing the effects of PAE would also be very important as we know that family preservation is paramount. Lastly, I believe that research to try to determine the correlation between trauma and attachment issues, and PAE would help more appropriate services evolve. There have been a number of trauma experts who have acknowledged the complexities of addictions within family treatment models, but often the role of PAE has not been a consideration when looking at the behavioural and mental health presentation of the child. This oversight, in my opinion often further perpetuates the difficulties for families attempting to heal, in terms of their feelings of failure and self and system blame when the parent-child relationship does not improve as expected.

Conclusion

FASD assessment and support programs are necessary services, yet they are clearly out of reach for far too many in need. Research findings indicate that individuals are really struggling and that their difficulties are compounded by a general lack of awareness and understanding, the cost of assessment services, stigma and high prevalence rates as well as the lack of assessment opportunities and FASD informed supports and services available. The research also indicates that government expects that all children with complex needs are to be included within current system infrastructure, but sadly, this is not the case for those experiencing PAE and suspected FASD. Individuals, families and communities should not have to work so hard, and so independent of one another in order for individuals and families to be properly supported. FASD needs to have a strong voice, and government really needs to listen to the stakeholders, and acknowledge the various ministries' responsibilities and shortcomings.

All children have a right to be adequately assessed no matter what the potential disorder or disease may be. This is the only way that individuals affected will grow to meet their own potential. If a child struggles with weight, mood, fatigue, concentration or sleeping habits, the parent or caregiver would go to the doctor and not stop with appointments and consultations until the child was properly diagnosed. If the child is diagnosed with diabetes, then the parent or caregiver would not be expected to leave the hospital or diagnostic clinic without the opportunity to learn what was needed in order to ensure that the child would receive the best possible treatments and supports. The parent would seek and receive resources to share with the child's school and support networks in order to mitigate the risks of primary complications, as well as potential secondary problems. Why is this not the case for those individuals experiencing significant and varied challenges, and who have had PAE in this affluent province of Ontario? It remains puzzling to many FASD advocates, how many people (professionals included) dismiss the role of PAE. It is also difficult to see how hard families have it trying to parent the unique and unpredictable needs of their children, so often in isolation, while simultaneously educating others and advocating for services.

It is the dream of this researcher that in five years or less, people will not have to advocate so hard in order for families to have access to the supports and services that they simply should have access to. The suggestions and recommendations outlined in this report will be helpful to many beyond the 1-5% of the general population who are now estimated to be directly affected by FASD. There is very real potential for families to do much better, and for fewer babies to be born with PAE. Finally, the emotional and financial cost savings that will come to be as a result of such investments will be ‘game changing’ and quite profound.

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Appendix A: FASD neurobehavioural screening tool

Sample questions from the FASD Neurobehavioural screening tool to help clinicians differentiate FASD from other mental health, behavioural and developmental disorders before referring for a full assessment.

1. Has your child been seen or accused of or thought to have acted too young for his or her age?
2. Has your child been seen or accused of or is thought to be disobedient at home?
3. Has your child been seen or accused of or is thought to lie for cheat?
4. Has your child been seen or accused of or is thought to lack guilt after misbehaving?
5. Has your child been seen or accused of or thought to have difficulty concentrating, and can't pay attention for long?
6. Has your child been seen or accused of or is thought to act impulsively and without thinking?
7. Has your child been seen or accused of or is thought to have difficulty sitting still is restless or hyperactive?
8. Has your child been seen or accused of or is thought to display acts of cruelty, bullying or meanness to others?
9. Has your child been seen or accused of or is thought to steal items from home?
10. Has your child been seen or accused of or is thought to steal items outside of the home?

This screening tool is to objectively augment the clinical judgement of the provider to determine suitability for a full FASD assessment. Prenatal exposure to alcohol needs to be confirmed as well as part of the screening process.

The FASD screening and referral tool for youth probation offices focusses on historical difficulties and developmental concerns that required interventions. Additionally, the questions focus on previously diagnosed mental health conditions as well as previous involvement with youth justice and child welfare agencies. If this tool indicates that there has been a pattern of historical difficulties that are compounded with higher expectations, then if FASD assessment services are available, it would be recommended that a referral move forward for this youth.

(Maynard, 2012)

Appendix B: Visible and invisible features of FASD

A young boy with facial features associated with PAE; flat upper lip, flat philtrum, and eyes slightly smaller and spaced wider apart which lead to a diagnosis of Fetal Alcohol Syndrome.

Morgan Fawcett is an adult living with FASD with no visible facial characteristics.

A beautiful infant with confirmed PAE, developmental lags and possible observed sensory issues. This girl has no obvious growth restrictions nor facial features yet is more representative of the majority of those affected by PAE and have a Fetal Alcohol Spectrum Disorder.

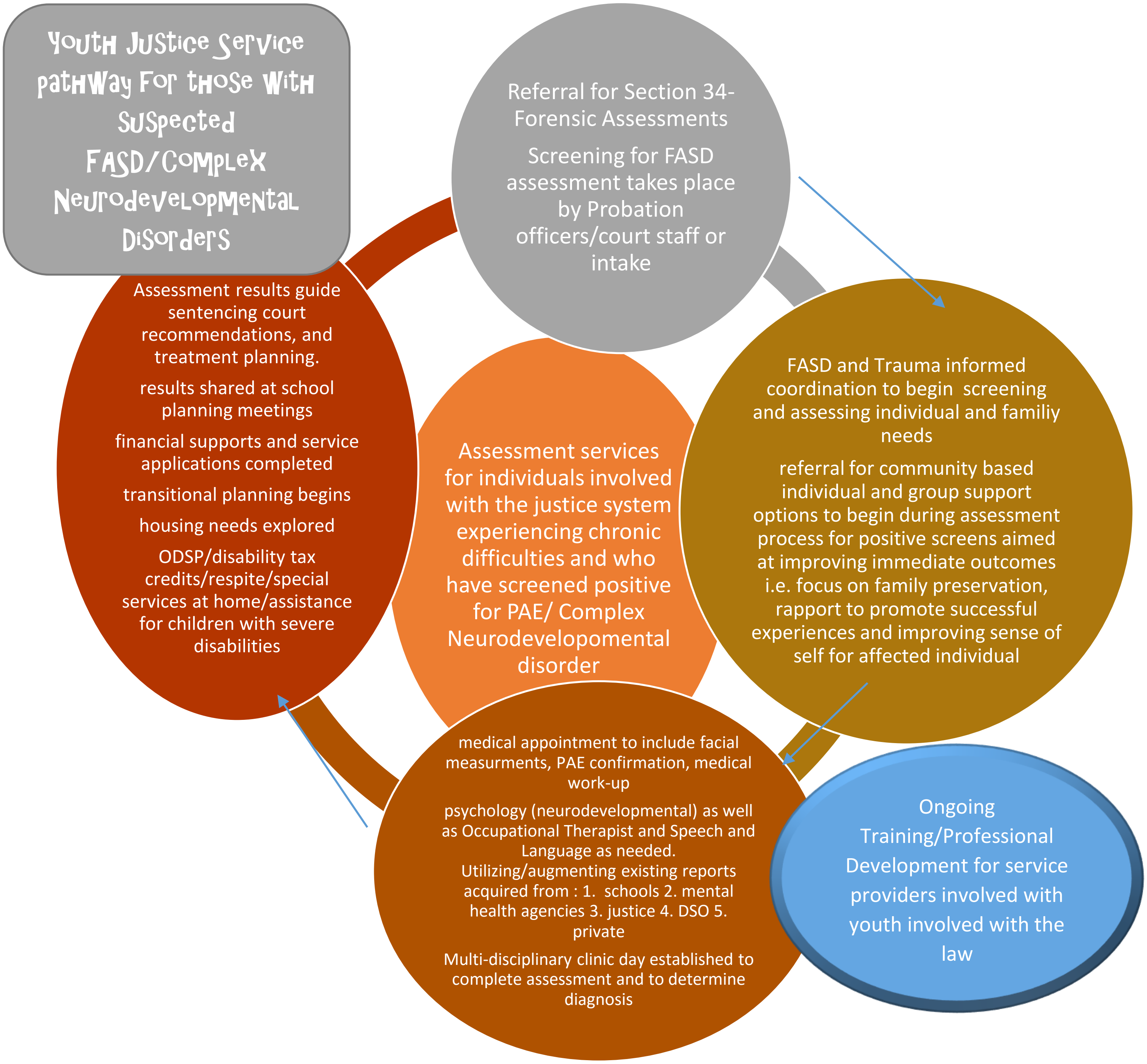
Appendix C: Chart Review

Chart review: Cost analysis of services offered prior to PAE screen

Intervention	Cost
Psychology assessment	* 2 = 5000.00
Tyke Talk assessment and treatment	1500.00
Speech and language assessment	2000.00
Family Doctor visits and referrals	* 10 = 1400
Developmental pediatrician consults	* 7 =2800
Psychiatric Consults	*16 = 3200
Occupational Therapist assessment and treatment	*2=6000
Residential Treatment(which is contraindicated for those with FASD and Attachment disorders)	$72 000.00
Mental Health Treatment groups	1000.00
	Estimated total = $94 000
Number of diagnosis placed on this nine year old girl	6

(London Family Court Clinic, Child Parent Resource Institute [LFCC, CPRI], 2014, p. 33)

Appendix D: Care paths at various system points of entry



Youth Justice Service pathway For those With Suspected FASD/Complex Neurodevelopmental Disorders

Assessment services for individuals involved with the justice system experiencing chronic difficulties and who have screened positive for PAE/ Complex Neurodevelopomental disorder

Referral for Section 34- Forensic Assessments

Screening for FASD assessment takes place by Probation officers/court staff or intake

FASD and Trauma informed coordination to begin screening and assessing individual and familiy needs

referral for community based individual and group support options to begin during assessment process for positive screens aimed at improving immediate outcomes i.e. focus on family preservation, rapport to promote successful experiences and improving sense of self for affected individual

medical appointment to include facial measurments, PAE confirmation, medical work-up

psychology (neurodevelopmental) as well as Occupational Therapist and Speech and Language as needed. Utilizing/augmenting existing reports acquired from : 1. schools 2. mental health agencies 3. justice 4. DSO 5. private

Multi-disciplinary clinic day established to complete assessment and to determine diagnosis

Assessment results guide sentencing court recommendations, and treatment planning.

results shared at school planning meetings

financial supports and service applications completed

transitional planning begins

housing needs explored

ODSP/disability tax credits/respite/special services at home/assistance for children with severe disabilities

Ongoing Training/Professional Development for service providers involved with youth involved with the law

Tertiary care/hospital based Service pathway for those with suspected FASD/Complex Neurodevelopmental Disorders

Referral to hospital or tertiary MH services for severe/crises Mental Health concerns from self/family/community agency/internal

FASD/Complex Neurodevelopmental Disorder and Trauma informed coordination to begin screening and assessing individual and familiy needs

referral for individual and group support options to begin for positive screens aimed at improving immediate outcomes while simultaneously assessing for a possible diagnsosis i.e. focus on family preservation, rapport to promote successful experiences and improving sense of self for affected individual

medical appointment to include facial measurments, PAE confirmation, medical work-up

Inpatient services to include psycho-educational assessment as well as Occupational Therapist and Speech and Language as needed. Collatorals gathered and existing assessment findings utilized and augmented from: 1. schools 2. mental health agencies 3. justice 4. DSO 5. private/contracted 6. internal reports

Multi-disciplinary clinic day established t complete assessment and to determine diagnosis

Assessment results guide treatment planning that is family centered and holistic.

financial supports and service applications completed

transitional planning begins as needed

housing needs explored

ODSP/disability tax credits/respite/special services at home/assistance for children with severe disabilities

assistance with life skills within existing community programs and ongoing advocy and system navigation

Mental Health treatment accessed at hospital or tertiary care Mental Health agency for individuals and families experiencing severe, chronic and complex difficulties. Intake process has determined a need for inpatient treatment and positive screen of PAE and possible Complex Neurodevelopmental disorder

Ongoing clinician capacity building

Ongoing and coordinated linkages with community based long term supports

Community Based Mental Health Service pathway For those With Suspected FASD/Complex Neurodevelopmental Disorders

Referral to Children's Mental Health, Adult Mental Health Services from self/family/community agency/internal

FASD/Complex Neurodevelopmental Disorder and Trauma informed coordination to begin screening and assessing individual and familiy needs

In house individual and group support options to begin for positive screens aimed at improving immediate outcomes while simultaneously assessing for a possible diagnsosis i.e. focus on family preservation, rapport to promote successful experiences and improving sense of self for affected individual

Mental Health treatment accessed at an Community Based Mental Health agency for individuals and families experiencing chronic difficulties. Intake process has determined a positive screen of PAE and possible Complex Neurodevelopmental disorder

referrals for psycho-educational assessment as well as Occupational Therapist and Speech and Language as needed. Possible resources: 1. schools 2. internal/mental health agencies 3. justice 4. DSO 5. private/contracted 6. internal psychologist

medical appointment to include facial measurments, PAE confirmation, medical work-up

Multi-disciplinary clinic day established to complete assessment and to determine diagnosis

Assessment results guide treatment planning.

results shared at school planning meetings

financial supports and service applications completed

transitional planning begins as needed

housing needs explored

ODSP/disability tax credits/respite/special services at home/assistance for children with severe disabilities

case management/assistance with life skills within existing community programs

FASD Centre of Excellence

Ongoing clinician capacity building efforts, i.e. training, consultation, and mentoring.

Ongoing and coordinated Service provider training re: FASD informed supports and services

Community Based Primary Health Care Service pathway for those with suspected FASD/Complex Neurodevelopmental Disorders

Referral to Community Based Primary Health Care Agency from self/family/community agency/internal

FASD and Trauma informed coordination to begin screening and assessing individual and familiy needs

individual and group support options to begin for positive screens aimed at improving immediate outcomes while simultaneously assessing for a possible diagnsosis i.e. focus on family preservation, rapport to promote successful experiences and improving sense of self for affected individual

Holistic care accessed at an AOHC member agency for individuals and families experiencing chronic difficulties and who have complex behavioural difficulties and/or suspected Neurodevelopmental disorder

medical appointment to include facial measurments, PAE confirmation, medical work-up

referrals for psycho-educational assessment as well as Occupational Therapist and Speech and Language as needed. Possible resources: 1. schools 2. mental health agencies 3. justice 4. DSO 5. private/contracted 6. internal psychologist

Multi-disciplinary clinic day established to complete assessment and to determine diagnosis

Ongoing prenatal screening, and prevention efforts.

Ongoing clinician, individual, family and community capacity building and advocacy efforts

Assessment results guide treatment planning.

results shared at school planning meetings

financial supports and service applications completed

transitional planning begins

housing needs explored

ODSP/disability tax credits/respite/special services at home/assistance for children with severe disabilities

case management/assistance with life skills within AOHC programs

AOHC is Association of Ontario Health Centres