Chapter 15
FASD and Child Welfare

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Introduction

Fetal alcohol spectrum disorders (FASD) is a disability that requires lifespan support. The primary response to FASD emerged in North America and was particularly influenced by the Jones and Smith publication in 1973, which identified disabilities caused by alcohol exposure [1]. The life course model posited has relevance to FASD and will be integrated in this chapter [2]. The life course of a person with FASD needs to include the prenatal period, infancy, childhood, adolescence, and adulthood, and each stage comes with unique developmental tasks. Child welfare can become involved at any of these stages including adolescence and adulthood when individuals with FASD become parents. It is critical to recognize that child protection concerns exist at all stages, but it is often in early life that child

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welfare becomes involved due to the challenges associated with parenting and alcohol and substance use disorders.

The UN Convention on the Rights of the Child is described as a human rights treaty for children that recognizes all children have rights to develop and grow, and the consideration of the best interest of the child is at the forefront [3]. The Convention on the Rights of Persons with Disabilities was adopted by the United Nations in 2006 and enacted in 2008 [4]. The child welfare system is focused on the rights of children to be safe in their families and communities. Children with disabilities and FASD in particular often face multiple adversities including historical trauma in the family, social isolation, and stigma. It is critical to note that FASD is not well recognized globally as a childhood disability. Internationally, most children involved in child welfare are unlikely to be screened and assessed for FASD, having limited access to supports that could help improve their quality of life [5]. The intersection of FASD and child welfare is critical, and the need to recognize FASD in frontline child welfare practice is essential for both prevention and intervention.

The role of child welfare at its core foundation is to assure the survival, security, and development of children and families. Child protection issues such as failure to meet the care and developmental needs of children, neglect, and abuse are primary reasons for removal from parental care. Women with substance use disorders often have traumatic histories and mental health problems that can contribute to the removal of children from their care and intergenerational transmission of maltreatment. Given these experiences and often punitive policies, many families are fearful of the child welfare system [6]. However, it has been noted that recognition of FASD in an infant or child offers a crucial opportunity for intervention for both mother and child. Programs such as PCAP (Parent Child Assistance Program) have made substantial contributions in supporting mothers and children involved in child welfare, including reduced alcohol use in pregnancy [7, 8].

Children with FASD are overrepresented yet underrecognized in the child welfare population. Misconceptions of FASD and stigma have played a pivotal role in the lack of FASD diagnosis. The adequate provision of services in childhood, adolescence, and adulthood globally is problematic. FASD may go unrecognized in a child for many years and often the disability is not picked up until children enter the school system or when unexplained behavioral challenges become problematic [9]. Adequate screening and documentation of prenatal alcohol exposure are needed across all systems of care, including child welfare, to effectively identify people with FASD and support children and families. When children have behavior problems, there is a tendency to blame the parents instead of localizing the disabilities associated with FASD. Parents of children with FASD experience high levels of stress, more so than those of children with other developmental disabilities [10]. Creating sound interventions for children and youth with FASD is essential.

Stigma is a major contributor to FASD going unrecognized and underserved. Public stigma of FASD is pervasive across the globe [11, 12]. Stigma contributes to shaming and blaming of women and discrimination of people with FASD. It also creates internalized self-stigma and feelings of low self-worth. Often, we know very little about the lived experiences of children with FASD who end up in the child welfare system and grow up in care. Parents who use alcohol during pregnancy often face life adversities and the use of alcohol is not done with an intent to cause harm to the developing fetus, but rather is a function of interpersonal challenges they are experiencing [7, 8]. For example, Myles Himmelreich who lives with FASD is a well-known public speaker who grew up in the child welfare system and speaks to the effects of this stigma. Myles provides training on FASD, is a father and an advocate for many living with this disability and takes the position that harmful messages about alcohol use and pregnancy can contribute to stigmatizing the person who lives with FASD. In a recent report, Myles stated the following:

> FASD is caused when there is alcohol intake during the pregnancy. This can happen for a number of reasons but please know statements like "FASD is 100% preventable" just leads to more shame and blame. Statements like "The child's mother should have cared enough to not drink" lead to stigma for the mother and child. My mother drank; I have FASD. This is what I HAVE—not who I AM. This is what the children and youth in this report HAVE—not who they ARE [13].

The voice of Myles informs us that it is critical to recognize that the disability of the person who lives with FASD was formulated by pre-birth experiences and often difficult circumstances of families where alcohol use leads to FASD. The identity of the person living with FASD is shaped by many influences, and individuals with FASD are their own persons who want to live and experience life on their own terms. In Myles's case, his experience of growing up in the child welfare system has become a critical tool he has utilized in sharing knowledge about FASD as a successful public speaker, despite having many early disadvantages to overcome.

The stigma and lack of empathy experienced by families with FASD are accompanied by a pervasive lack of understanding about the effects of FASD across systems of care, including child welfare [11]. Families where FASD is a concern often come to the attention of child welfare due to concerns such as poverty, risky behavior of their child, mental health concerns, substance abuse, and issues of neglect [14]. Case workers receive little, if any, training on FASD, and child welfare systems are rarely set up to effectively screen and intervene with this population [15]. Running parallel are the universal voices from foster carers/kinship families raising children with FASD who are experiencing a lack of support, respite, and training. Increasingly, advocacy and access to FASD diagnosis occur when adolescents with FASD involved in the child welfare system become enmeshed within the criminal justice system [5]. This could be addressed and even prevented with adequate screening and supports earlier in their time in care.

Epidemiology of PAE and FASD in Child Welfare and Related Settings

In 2021, almost 50 years after the initial publication on fetal alcohol syndrome, FASD continues to be a leading cause of developmental disability globally [see Chap. 1]. Recent research has identified that limited knowledge exists overall about children with prenatal alcohol exposure in the child welfare system despite the significant role that alcohol has in parental involvement with the child welfare system

[16]. Data collected on 547 children and youth in the US who had been adopted or were in the foster care system concluded that 156 children met the criteria for FASD diagnosis and 125 (80%) had not been diagnosed as having prenatal alcohol exposure [9]. Globally, the themes of undiagnosed and unrecognized FASD have emerged over the past decade across child protection, criminal justice, and health sectors, and this identifies a significant gap in knowledge about FASD amongst professionals [9, 11]. The issue of FASD prevalence is taken up by Popova in Chap. 1 and highlights the global concern of FASD as a critical public health problem of particular concern to children and families. It was identified that there is a 6.0% prevalence rate of children with FASD in the child welfare system and children in the child welfare system are at risk for FASD [17, 18]. While the estimated global prevalence of FASD among special subpopulations, which includes children in care, is identified as 7.7 per 1000, epidemiological research has identified that in the United States the prevalence rate is noted to be 32 times higher in special subpopulations such as children in child welfare care in contrast to the general population [17]. Globally, the overall estimated prevalence of FASD in special subpopulations is considered to be 10–40 times higher than the general population [17] which raises credible concerns about the need to engage in supports for prevention.

Child Welfare Policies Toward PAE and FASD

There are many reasons why individuals may use alcohol prenatally and substance use is a leading reason for parental involvement in the child welfare system [16]. The use of alcohol during pregnancy relates to the same social determinants that influence alcohol use more generally. Many of these reasons include being unaware of their pregnancy, not understanding how alcohol may affect an unborn child, partner or peer pressure, mental health and addictions, and trauma that may include intimate partner violence or victimization. It has been shown that individuals who give birth to children later diagnosed with FASD have higher rates of inadequate prenatal care and experience significant social disparity [19]. Importantly, it has also been shown that both low parental empowerment and parental mental health are important reasons why women may use alcohol [20]. Individuals can also receive conflicting information regarding use of alcohol, particularly in small quantities, during pregnancy [21]. The harmful use of alcohol is a serious health problem and vulnerable populations including those in corrections and the child welfare system are 10–40 times at higher risk for FASD than other populations [17].

In North America, prevention programming and child welfare are generally of the view that no alcohol is acceptable in pregnancy with several states in the US taking the position that alcohol use in pregnancy is child abuse [22]. This is not so in Canada as a result of a Supreme Court of Canada decision concluding that a fetus is not a child within the meaning of child protection [23]. The issue of child welfare involvement due to prenatal substance exposure remains a key public health concern [24] as alcohol exposure has particular health risks impacting fetal growth and contributes to low birth weight [24, 25]. Further, lifelong adverse effects can include impacts on emotional, behavioral, developmental, and cognitive functioning. Children with these challenges who do not have the benefit of their disability being recognized by child welfare have limited opportunity to receive beneficial therapeutic interventions [26].

It is reported that 50–80% of child welfare cases include a parent who uses substances and this is a serious concern given the problems associated with parenting and family functioning, birthing parents being most often involved with the child welfare system [27]. The child welfare system tends to see the child as the client and the complexity of parental substance use require a different lens be applied when considering interventions. This research suggests models such as the Parent Child Assistance Program PCAP—a program that provides home visitation and mentoring to women, including supporting women in accessing treatment programs involving their children, can demonstrate positive benefits [13].

A recently published US report, *Prenatal alcohol and other drug exposures in child welfare study,* identified substance use, socioeconomic and racial/ethnic disparities contribute to involvement in the child welfare system. Substance use by marginalized populations was identified as a significant concern in this reporting noting, “A disproportionate number of Black and low-income women are reported to child welfare because of substance use during pregnancy” (p. iv) [26]. Active parental substance use creates conditions for involvement with the child welfare system and contributes to the risk of loss of parental rights in contrast to those not using substances [28, 29]. Many health and social concerns are noted to be key intersections where active substance use is identified in a person’s life such as mental health problems, stress, being a single parent, social isolation, historical trauma, childhood sexual abuse, housing insecurity, unemployment, poverty, and experiences of violence and abuse [27]. This research noted that severity of substance abuse was a key factor leading to out of home child placement [27]. In the US, the Child Abuse Prevention and Treatment Act and the Comprehensive Addiction and Recovery Act passed in 2016 compels states to develop policy and practice plans related to the “safe care” with a particular focus on infants and caregivers [24]. Further, the level of intervention in more serious cases is often determined and defined by both the intensity of FASD related behaviors and the social locations of the parents. It is noted in the US that 23 states identify prenatal substance exposure [PSE] as child abuse, thus contributing to criminalization of mothers who use substances [24]. Mandated reporting of positive substance screening remains in place for many health care providers [24], and it was noted that information on substance use is either disclosed through self-report or toxicology testing [25].

When a referral or report is made to child welfare regarding a child with prenatal substance exposure who is deemed to be at risk, investigations are often undertaken to determine risk and assess safety issues. If intervention is required, it can range from the least intrusive approach which is the provision of support services to families in their home, or the most intrusive approach which is child removal [24]. Safety concerns for infants are paramount given their vulnerability and risk, and in a review of national foster care data in the US from the Adoption and Foster

Care Reporting System (AFCARS) it is reported that confirmed prenatal substance exposure is a factor in child removal in almost 35% of cases reported to child welfare [30]. In this research, infants were identified as children under a year and it was noted that for infants removed due to substance use, there were additional leading reasons for removal from parents including neglect, inadequate housing, caregiver inability to cope, physical abuse, parent incarceration, and disability (86% of cases) [30]. For infants where substance use was the primary reason for removal, it was noted that they were more likely to remain in care, even when a goal of reunification with parents or relatives was documented on their case plans [30]. This suggests that active parental substance use is considered to constitute risk, particularly for infants. This unique study of infants removed due to substance use offers insight into the early life trajectory and experiences with the foster care system.

Child Welfare and Families

Biological parents of children with FASD diagnosed in clinical settings often do not raise their children, which is attributable to many cumulative disadvantages [19]. Pivotal research conducted in Seattle profiled the experiences of 80 birth parents and noted that an FASD diagnosis for their child provided an opportunity to provide care and prevention services to individuals who were at risk of further alcohol exposed pregnancies [20]. The researchers noted that within this sample, 95% of individuals had been physically or sexually abused during their lifetime, 96% had 1–10 mental health disorders, and 61% did not complete high school. Although many individuals demonstrated the ability to overcome their alcohol dependence, they experienced many barriers to accessing substance use, mental health, and reproductive health treatment and support. Alcohol use was also noted to be intergenerational, with parents of children with FASD potentially having FASD themselves [20]. Individuals with FASD are likely to have their children at a younger age than individuals without FASD [31], highlighting their own vulnerability in personal relationships. When FASD is not recognized, the risk of intergenerational cycles exists and there is a high risk for ongoing prenatal alcohol exposure in subsequent generations [32]. Adult diagnosis of FASD remains a developing field and access is fragmented and limited [33], yet it is critically important in child welfare involvement to know if parents have FASD [34].

It is known that when an individual gives birth to a child after prenatal alcohol exposure, the likelihood exists for further affected births without intervention [7]. For example, in a 2008 Australian study research reports that among 65% of children with FASD, with almost half reported to have a sibling with FASD [32]. Biological mothers who have substance use disorders often face many challenges, frequently are single parents and are more likely to be reported to child welfare due to their substance use [30, 35] and to have their child taken into care [36]. There is a strong association between active substance use and perceived risks to infants and children by the child welfare system [37]. In one study, single women with mental health issues were identified as more likely to report their substance use during pregnancy than women who were married and it was suggested that clinical screening for these problems can offer a critical point of intervention in prenatal care [38].

Child welfare often plays a critical role in the lives of families of children with FASD for several reasons including active substance use disorders and challenging child behaviors. Children with FASD are at risk of child welfare often due to what is identified as neurobehavioral problems and it is noted that challenging behaviors are often the reason for referral for support and clinical intervention [9].

Parents who have FASD were involved in a Canadian study identified their desires to break the cycle of addiction in future generations and in the voice of one parent:

> When I grew up, my mom and dad used to always drink around me, and I don't want that. I want to break that cycle, and I don't want to live like that. ... I don't want my kids to have to go through that. So I don't really hang around people who drink or do drugs [39].

Parents identified challenges in working with child welfare and being stigmatized due to the "label of FASD client" [39 , p. 357], often feeling misunderstood and judged by workers with limited knowledge about FASD. Parents with FASD face many barriers including a constant fear of losing the custody of their children and feel particularly vulnerable due to poverty and housing insecurity. A major policy and structural barrier for adults with FASD is that they often do not quality for disability supports [39]. The need exists for FASD informed care in responding to the child protection needs of children and families and this is particularly needed when parents themselves have FASD. It is important to recognize that the parent with FASD requires interventions that are strength-based and person-centered so that accommodations can be provided that consider both relationships and safety [40].

The work done by researchers in British Columbia, Canada has outlined a strengths-based intervention model of FASD informed care for parents who have FASD. There are several best practices including: (1) adopting a non-judgmental and non-stigmatizing approach; (2) using respectful person first language that is clear, concrete, and easy to understand; (3) checking in with the person to ensure they are understanding what is being communicated; (4) offering reminders and use of tools such as visual calendars; (5) providing support through coaching, modeling, and hands on support; (5) setting realistic goals and breaking those down into steps that are achievable; (7) ensure service providers involved with the family have FASD training; (8) provide an individualized and flexible approach to the individual; (9) use outreach support and one-to-one work; (10) use a wholistic, wellness based approach in working with the individual; (11) consider the broader needs of the individual as a person and beyond being a parent; (12) involve a healthy support network of family or other support persons; and (13) attend to the physical environment to ensure it is not overwhelming the person [40].

FASD Screening and Recognition Within Child Welfare

FASD is an etiologic diagnosis that describes specific physical and neurobehavioral characteristics resulting from prenatal exposure to alcohol. The diagnostic assessment is intended to provide understanding of this constellation of features in an individual child and recommend early intervention that is informed by the assessment. The interested reader can learn more about available diagnostic systems and process for evaluation in Chaps. 8 and 9 of this book. Points particularly relevant for the child welfare system will be emphasized here.

The diagnostic assessment of FASD generally requires documentation of PAE. However, documentation of prenatal alcohol exposure in the medical record is often lacking [8]. Prenatal visits and delivery are sensitive times for gathering this information which is best gathered in a trusting and non-judgmental environment with opportunity for harm reduction and supportive intervention available. Visits with a healthcare provider who is trauma informed and culturally sensitive as well as FASD informed is critical to gathering this information which then allows for discussion of PAE and early recognition of affected children. However, it is equally important to recognize mothers who may be unwilling to disclose their alcohol use in pregnancy for fear that the child will be apprehended by child welfare. If the mother has other children, she may fear loss of them as well. In addition, if the mother has her own child welfare history, that, along with a disclosure of use in pregnancy, will almost certainly lead to a referral to child welfare.

Alcohol is also often not the only prenatal exposure, with tobacco and other drugs commonly used. In a Canadian study looking at the complexity of prenatal exposures in children, 82% were found to have multiple exposures [41]. This is consistent with data from the CanFASD Dataform which documents nicotine, cannabis, cocaine/crack, and prescription medications as among the most common co-occurring exposures [42]. The need exists to conduct routine screening for prenatal alcohol exposure given the well-known challenges and neurodevelopmental problems faced by individuals with FASD [42]. It is reported that screening for FASD is often inconsistent, and some support exists internationally for in-school screening to identify cases of FASD [43]. Children who come into care are routinely assessed by a primary health care provider and physicians are well positioned to screen for concerns about alcohol use in parents or prenatal alcohol exposure in children [18]. In relation to children with PAE screening can also assess for child maltreatment, academic and social problems, mental health disorders, behavioral problems, communication skills, educational concerns, physical health issues such as sleep, dental problems, nutrition and growth, and facilitate referrals for appropriate professional supports [ah]. The primary health care provider can also facilitate referrals to child welfare if child protection concerns exist and play a key role in supporting children and foster care providers when children are placed in care [18]. As earlier identified, given the strong connection between alcohol use and child welfare involvement, and the concern about child protection issues for children with PAE and FASD, a critical need exists to develop protocols and practices within child welfare to engage in

FASD informed practice. The reason this is essential is that screening, assessment and diagnosis support the best outcomes for children who have FASD as they are often cared for in the child welfare system [18, 31, 42, 44, 45].

It has been identified that inconsistent approaches to screening for PAE and FASD are a concern in the child welfare system. A notable research project is reported by the Children's Aid Society of Toronto that involves the application of a Neurobehavioral Screening Tool (NST) to screen children and youth coming into care [46]. This brief screening tool asks questions related to behaviors, impulsivity, and hyperactivity and completed by the assigned child protection worker (CPW). There were 106 children and youth involved in this research aged 3–15 and of the 18 children suspected to have FASD, 14 received this diagnosis. This collaborative model of care that includes child protection workers from the outset through engaging in neurobehavioral screening demonstrated the benefit of screening for FASD in child welfare cases. This approach was effective, and psychiatric comorbidity was identified for all youth referred for FASD diagnosis. It was also noted that the psychiatric referrals led to medications being started or changed as necessary and psychosocial concerns for youth were identified leading to recommendations about support needs in their living environments. This research showcased the direct benefit of a collaborative screening and assessment model involving child protection workers, pediatricians, and psychiatrists and strongly recommends the engagement of the CPW in screening for FASD for children involved in child welfare care [46].

Following routine screening, children at risk for an FASD diagnosis should be referred for comprehensive evaluation. The presentation of FASD is often complicated by exposure to trauma and social stressors. The differential diagnosis of FASD requires careful consideration of prenatal and postnatal influences on physical, emotional, and cognitive development that may contribute to behavioral assessments and functioning. In recent work characterizing adverse prenatal and postnatal experiences in children, 2/3 of children in a clinical cohort had experienced both prenatal and postnatal adversity [41]. In the same study, over 80% of children had been prenatally exposed to multiple substances. All of these factors warrant balancing and consideration in a diagnostic assessment.

In a study that examined the relationship between prenatal substance exposure, adverse childhood experiences, and mental and behavioral disorders conducted in Finland, it was noted that exposed children had higher prevalence of diagnosed mental and behavioral disorders (55%) in contrast to the controls (26%) [47]. It was also noted that of those exposed that 8% had an FASD diagnosis while 51% had multiple substance exposures including smoking during the pregnancy (75%) in contrast to the controls (19%). A serious concern noted in the out of home care group was that mothers had a death rate of 15% stating that mothers themselves had a behavioral or emotional disorder diagnosis (77%). It was identified that children and youth with behavioral and emotional disorders who had experienced out of home care were also diagnosed with disorders related to psychological development, mood, stress, and sleep. This was attributed to what was identified as "PSE is associated with a high accumulation of ACES and ACEs independently increase the risk of mental and behavioral disorders. The risk was highest among youths with

PSE (prenatal substance exposure), OHC (out of home care) and a high rate of maternal risk factors" (p. 10). This research identifies the critical point that child welfare involvement needs to consider the mother-child dyad in intervention given the risks for both parent and child.

Concerns and Health Issues for Infants and Young Children

In 2014, the Adoption and Foster Care Analysis and Reporting Systems report indicated that over one-third of children coming into care in the US were infants and young children under five, the largest age group of children coming into care. The number of foster care entries attributable to parental drug use increased 147% between 2000 and 2017 primarily due to increased use of illicit substances including opioids [48]. From 2004 to 2016, the incidence of Neonatal Abstinence Syndrome (NAS, also known as NAS, Neonatal Opioid Withdrawal) increased from 1.6 to 8.8 per 1000 hospital births [49].

Infancy and early childhood are critical stages for identifying the risk factors of prenatal alcohol exposure, as the first 3 years of life is the period of time when the most rapid physical and developmental growth takes place. Infants with FASD may present with small for gestational age or low birth weight growth patterns, prematurity, and decreased length and head circumference in some cases [50]. Related infant health issues associated with prenatal exposure to alcohol and other substances include sudden infant death syndrome (SIDS or crib death), infectious diseases (including hepatitis B and C, HIV, methicillin-resistant *Staphylococcus aureus* (MRSA), and syphilis) if mother tested positive for these infections while pregnant, and breathing problems.

In the very early years of life and if the child is living in a supportive environment, evidence of developmental delays may not apparent [51]. As the developmental stage advances toward emerging independence, problem solving, and abstract reasoning, children with FASD begin to demonstrate more challenges. In infancy and early childhood, problems with self-regulation tend to be most notable [52]. This can include negative affect and difficulties in arousal regulation, stress reactivity, impulse control, sensory integration, early attention skills, sleep and more. They may also show difficulties in fine and gross motor function, coordination and balance, and lowered adaptive functions [52].

Infants and toddlers presenting to child protection services, with or without prenatal substance exposure, may have experienced maltreatment as well as disruptions in their relationships with primary caregivers at a point where these relationships are critical for development. Because their healthy development is interrupted by the lack of security and attachment from their primary caregivers, infants and toddlers in foster care are vulnerable to the effects of neglect, maltreatment, and multiple placements, which can have lifelong implications if not addressed [53]. Alternatively, younger children may have entered foster care from the home of substance-using birth parents and may have experienced irregular and inconsistent daily care.

Developmentally appropriate services are needed at every stage of maturation, starting early. A supportive environment during the first 3 years of life can have a positive impact on long-term outcomes of the children. The benefits of providing early intervention, even without a formal FASD diagnosis, are significant with lifelong impacts, including increasing the possibilities of them returning to birth families or experiencing a timely adoption process, identifying health and developmental issues early, and providing a caregiving environment that supports the best possible outcomes.

Most interventions and programs available through child welfare for substance-exposed infants and young children are focused on attachment and mental health [54]. Healthy development of an infant is influenced by the interactions between the infant, the caregiver, and the environment. Two factors which are of great importance in caring for substance-exposed infants are attuned caregivers and supportive environments. Researchers have found that parents and caregivers of special needs infants focus so much on the needs of the infants that they neglect their own well-being. Foster parents consistently identify the feeling of being supported as key to their success and satisfaction with fostering. Support for parents and caregivers can include respite services, childcare, and parenting resources. Birth mothers may also be coping with a mental health issue such as postpartum depression.

Diagnosis before the age of six has been identified as a key protective factor for children with FASD [55]. From a neurodevelopmental viewpoint, tailoring or positively reframing parenting practices to address a child's cognitive-behavioral profile can support development and socio-emotional well-being [52].

Concerns and Health Issues for Children, Adolescents, and Adults

Symptoms of FASD in childhood reflect disordered self-regulation, sensory processing, memory dysfunction, and global developmental and adaptive delays. In the preschooler, significant language delays and difficulties with regulation of attention and disorganized behavior increase the impact of developmental delays. Behavioral dysregulation often with aggression is extremely challenging for parents trying typical means of control and correction with limited success managing their child. For the child in care, this can be a reason for failure of placements and multiple caregiving experiences which places the child further at risk for disordered attachment and emotional dysregulation.

School age children with FASD tend to show increasing difficulties as demands increase with maturation. These include cognitive impairments, learning disabilities, attention deficits, memory deficits, language problems, hyperactivity and behavioral dysregulation with sensory stimulation, difficulties with social judgment, and peer relationships [18]. School age children in care who experience instability in care arrangements and/or in schooling fall even further behind academically and struggle find social supports.

Consideration of FASD in adolescent youth may be missed, often having been seen by other providers who have provided mental health diagnoses. These youth may or may not be attending school where their symptoms may have been more easily recognized. Children in care, particularly those with behavioral challenges, often have multiple school placements creating uneven responses to the child's needs across different settings. They may have experienced considerable trauma and loss and may be using substances themselves. Their language difficulties are often overestimated and may be severe. Gaps in thinking can include difficulties with forming associations, predicting, abstract reasoning, cause and effect, and generalization. They may be very literal and miss subtle social cues. Impulsivity and distractibility impact learning and social behaviors. They may experience difficulty weighing and evaluating decisions and may have difficulty judging difficulty, safety, and danger leaving them at heightened risk of exploitation and victimization. As well, youth with FASD growing up in care typically lose many supports when they transition to adulthood [56]. As adolescents and adults, people with FASD increasingly struggle with organization and have difficulty managing time, money, free time, and schedules. They are often described as socially immature.

School age children and adolescents need routine, structure, and consistency across environments, but unfortunately children with FASD often experience trauma, vulnerability, and adversity. Involvement with child welfare is not uncommon in childhood and adolescence. It is critical to recognize that children with FASD have high needs, and supporting caregivers are important to maintain placement stability for children in care [49]. One particular program, Families Moving Forward, offers consultation and support to caregivers of children aged 3–12 who have PAE and provides critical support in parent/caregiver coaching, psychoeducation supports, and skill building with an aim of looking forward [57]. Currently research is being conducted on an app that will provide support to families in an innovative way [58]. This critical program recognizes that FASD informed care is essential in order to meet the needs of children and families living with FASD and supporting caregivers needs to be an integral part of case management in FASD [59].

In the first paper from the Canada FASD National Database examining adverse outcomes for children and youth with FASD in child welfare care ($N = 665$) in contrast to those in other living situations, it was discovered that youth over the age of 12 living in care report significantly higher rates of physical and sexual abuse, and legal problems as an offender [60]. Almost half the participants lived with either their biological parent or relatives (311), while 184 were in foster care, 136 in adoptive care, and 34 living in a group home. This research also signaled concerns about the risk of suicidal ideation in this population (39%), noting this risk was higher for those children with FASD living with their biological family (27.3%) in contrast to those living in care (21.7%) and the remaining (17.8%) in adoptive living situations. This research opens up areas for potential interventions, recognizing that many young people who are living with their families may require additional mental health supports [60].

A mixed methods study exploring the topic of FASD and suicide was undertaken to explore suicidality—those range of behaviors that include suicidal talk and behavior, suicidal ideation, suicide attempts, and death among children and youth in Canada [46]. A secondary analysis from the National FASD Database was undertaken and included records with PAE confirmed, FASD diagnosis confirmed, and suicidality identified on record. The average age of participants was about 17.5 years, and, in the examination of cases, it was noted that suicidality was identified in this population at almost 26%, a much higher rate than the average population in Canada (3–12%). Higher rates of suicidality were greatest for those with trauma and abuse histories (33.1%), for those with legal problems and for those in group home or institutional settings [46, 60]. A concerning finding was that almost 12% of children in the age range of 6–12 also reported suicidality which raises concerns about the urgent need to recognize risks and vulnerabilities for this population in relation to mental health and well-being.

In summary, it is critical that FASD informed case management be utilized in the care of children with FASD. Infants, children, and youth with FASD are a vulnerable population facing lifelong challenges and often come into care in adverse circumstances such as parental substance use [18]. Early intervention is critical wherever possible and young children benefit from stable home environments with structure and routine [49, 55]. Children and youth with FASD often have trauma histories, and clinical support is needed in dealing with these concerns. It has been identified that children with FASD are far more likely to be cared for and live in the child welfare system [57], and caregiver support is essential in child welfare. Children with FASD benefit from highly structured environments at home, in school and in the community. Families raising children with FASD benefit from disability support such as respite and relief and it is critical to support families in times of crisis as we know parents experience higher levels of stress [10]. Children and youth with FASD are a complex population and research on FASD and suicidality underscores the critical need for professional and caregiver training and support in case management [46, 61]. Challenges are significant in the transition to adolescence and adulthood and the need exists to monitor and support mental health challenges.

Life Course Cumulative Disadvantages Associated with FASD

Childhood trauma and adverse childhood experiences are part of the landscape of FASD and child welfare and this needs to be more broadly understood in child intervention. While it is recognized that children are at risk when active substance use is going on in a home, it is critical to appreciate that FASD alone presents a remarkable vulnerability. FASD due to the nature of its condition sets the stage for a lifetime of vulnerability—the effects of prenatal alcohol exposure on the brain and body cause inherent challenges. The individual with FASD from the time they are an infant is situated to be dependent on others and ideally will grow into adulthood with well-established interdependent relationships to help navigate life. However, the dependence of the child and the ability to have their needs met is entirely dependent on the social structure into which they are born and live. That is to say that the family into which the child is born is expected by society to provide care that will support the child's development and growth. It is in this early stage of life that trajectories are established and infants and young children whose needs go unmet will struggle over their lifetime.

The universal theme and the problematic narrative of the lack of awareness of FASD are unacceptable and must be challenged. Children in the child protection system remain at risk of not being screened and assessed for FASD, and as noted earlier, this is critical in supporting the prevention of further cases within the same family. Misconceptions of FASD and stigma around the cause—alcohol use during pregnancy, have played a pivotal role in the lack of FASD diagnosis and the provision of services throughout the world. Despite a growing body of substantial research legitimizing FASD as a neurodevelopmental disability, FASD is still not perceived and understood as a legitimate and accepted developmental disability and this population remains dramatically underserved and poorly understood [54]. This impacts the delivery of effective services aimed at ameliorating the social, emotional, sensory, physical, psychological, and neurological challenges children living with this disability experience.

Child Welfare Practice

Child welfare workers, supervisors, and managers work within a system that is socially constructed to address the safety and well-being of children. Although each worker has completed intensive child welfare training, there is tension between the academic, legislative, and emotional contexts of lived lives. This gray space between objectivity (required by legislation, policy) and subjectivity (preferred by the front-line worker) is the context in which decisions are contemplated and child welfare workers are human beings with individual experiences that inform their judgment and decision-making [62].

Awareness of FASD within child welfare systems is often inconsistent. There are few child welfare authorities who offer required training in disability or training in FASD. These topics are not usually part of the core required training when one enters the child welfare workforce. Given the numbers of children with prenatal exposure coming to the attention of child welfare, it is confounding that education about FASD is lacking [46, 49, 57].

It is often challenging for those working in the child welfare system to figure out the best ways to screen and assess for FASD in children on their caseload. Screening and case management are key roles in child welfare work. Most child welfare systems are also challenged with high turnover rates at the front line, which compounds these challenges. A systematic review of FASD policy and practice in the US child welfare system notes that none of the studies focused on the assessment and referral process or the support provided to foster families or staff training regarding prenatal exposure [45]. It should therefore be no surprise that those with FASD are underserved in primary care provision within the child protection, criminal justice, education, health, and disabilities systems.

When confronted with a complex situation that involves a child with a disability like FASD, the child welfare system struggles to understand the nature of the diagnosis and how to assess the impact of the disability in relation to child protection concerns. The nature of a spectrum disorder requires unique and individualized planning. Accessible community resources are generalist in nature and rarely specialized enough to meet FASD specific needs. The over representation of high incidence of mental health among individuals with FASD is well documented [46, 48]. FASD informed approaches in clinical settings, particularly in child welfare and mental health are imperative in order to do no further harm.

Caring for children and youth with FASD is important work that often requires supports to help families manage due to the high care needs associated with FASD as a disabling condition. One program providing interventions to families earlier identified in this chapter is the Families Moving Forward Program [58]. It is critical to provide therapeutic interventions to families and caregivers as ongoing support is important for children with FASD, whose high needs often go far beyond the capacity of families and caregivers. While providing therapeutic support to the family is important, child welfare casework can also positively impact families by providing services such as respite and relief. Respite and relief are often essential components in maintaining the placement of a child, whether that be with family or relatives, or foster carers. Loss and grief work is also critical to include in responding to FASD in child welfare practice. Loss occurs on so many levels and can include apprehension at birth and the profound experience of loss by the mother at this time. Child apprehension at any time represents a major loss for both the family and the child. There are many losses along the way when developmental milestones are not met, when children experience rejection and exclusion, and when their disability is not understood by those in their environment and accommodations are not made for the disability.

Understanding of the caregiver experience is critical for professionals working to support families raising children with FASD. Most caregivers of children and adults with FASD are not their biological parents, rather they are kinship, foster, or adoptive families and often have limited experience and knowledge about how to care for a child with distinct needs related to PAE [31, 63]. As a result, caregivers are more likely to require detailed information about the child's history, access to caregiver support groups specific to FASD, and community support to balance daily life with disability needs. In an exploration of the adaptability of 84 caregivers across urban and rural Ontario, it was noted that "the ways in which adaptation is achieved may be unique for families of children with FASD, as compared to other intellectual or developmental disabilities" (p. 160) [63].

Kinship families provide care to children with whom they have a familial, cultural, or community connection. Unlike foster care, kinship families do not apply for this role. Instead, they are contacted, often in an emergency situation or on an urgent basis and asked to provide a safe home. Many of the complexities that exist for foster parents exist for kinship families as well and are compounded by family dynamics, additional demands of taking on the responsibility for their relatives' children, a lack of knowledge of systems, and a lack of knowledge of FASD. The kinship family can feel their sense of privacy is challenged by the very nature of having the child welfare system involved in their lives, often unexpectedly. Kinship families may be reluctant to have multiple professionals in their homes while trying to maintain a sense of family autonomy. Family privacy may be incongruent with the high level of support required in caring for children with FASD.

Adoptive families accept the challenges of raising a child with FASD expecting that there will be appropriate support from the health and social systems. Historically however, adoptive families were not provided with background health information about their children, including prenatal alcohol exposure [54]. Adoptive parents have become vocal advocates for individuals with FASD across the life course more so than birth or foster families as they are not as constrained by stigma or child welfare system processes.

For all caregivers, the level of need, support required, and stress are significant factors contributing to a high risk for placement or family breakdown. Expert consultative support for caregivers is hit and miss, and service delivery continues to be fragmented for this population. The provision of adequate support by frontline social workers in child protection to caregivers impacts placement stability which has been directly linked to enhanced positive outcomes [49]. Engaging caregivers in case planning, putting them in the lead to determine the level of support that the family system requires and can withstand is critical for success. Looking outside the family system for additional support through school, community, friends, and family can result in a more balanced case management plan. Continued advocacy for children and youth with FASD is required in child welfare specifically, and children in child protection deserve to benefit from FASD informed care in the interest of social justice.

It is clearly identified that children and youth with FASD often go undetected in child welfare and justice settings [5, 9] and recent research from Western Australia illustrates this point. The Banksia Hill Detention Centre Study included 99 children who were assessed for FASD and a prevalence rate of 36% was found in youth who had a range of neurodevelopmental conditions [64]. Notably, only two of the young people had previously been assessed for FASD diagnosis before incarceration revealing significant gaps in screening and recognition of FASD in child welfare and in the community. These children who are already often involved in the child welfare system often have serious behavioral and social challenges due to a disability that goes largely unrecognized within child welfare services.

Conclusion

Children with FASD involved with child welfare are a high needs and vulnerable population. One aspect of vulnerability is the fact that FASD goes underrecognized and this contributes to risk for the child. It has been noted globally that children with

FASD are a vulnerable population and often excluded from mainstream disability services. Stigma in relation to FASD remains a significant problem. Lack of education and knowledge in child welfare, social services, education, justice, and health professions sectors remain a significant problem.

One of the biggest challenges facing the child welfare system in Canada, the United States, Australia, and other countries is the failure of child welfare and health professionals to recognize FASD among the population. This is particularly concerning when best practice is predicated on early diagnosis and intervention, and children have better outcomes the earlier that intervention begins. Given children with FASD often have trauma histories and adverse childhood experiences, it is critical that screening, assessment, and diagnosis occur in order to provide interventions to support positive developmental trajectories.

There is no universal model of child protection practice for children and youth with FASD and concerted efforts need to be made to establish national and international practice guidelines. We must act to provide FASD informed care predicated on training and consultation regarding the distinct disability needs of this population. Adopting a life course approach is crucial as FASD is a lifespan disability and points of intervention are critical at every developmental stage from infancy to adulthood.

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