

# Module 9

## Adverse Impacts

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## Introduction

People with Fetal Alcohol Spectrum Disorder have many strengths. They also experience challenges. This module will discuss, in general, the adverse impacts of Fetal Alcohol Spectrum Disorder (FASD).

Prenatal alcohol exposure (PAE) does not directly cause adverse impacts. PAE causes brain and body differences (primary disabilities). FASD “represents the intersection of complicated biological, family, community, and societal circumstances that increase the risk for social inequity, intergenerational trauma, and health disparity” (Flannigan, Harding, et al., 2020, p. 7).

Adverse outcomes can start in the early years and continue to develop as someone with FASD grows older. These outcomes happen because children and adults with FASD:

- have a disability that is often ‘invisible’ to people
- may live with significant impacts on executive functioning and receptive language
- have trouble meeting expectations
- experience repeated failures
- do not receive appropriate supports
- experience stigma
- find it difficult to fit into a world that does not understand, and/or accommodate prenatal alcohol exposure (PAE)

The invisibility of FASD contributes to the numerous social and systemic challenges and barriers that people with FASD experience in daily life.

Gelb & Rutman (2011, p.8)

For many years, the term ‘secondary disabilities’ was used to describe these

Replace the term ‘secondary disabilities’ with: ‘adverse outcomes’, ‘challenges’, ‘impacts’, or ‘risks’.

Canada FASD Research Network (2021, p. 6)

impacts. This term is no longer recommended because ‘secondary’ implies these challenges are not as important or noticeable as the primary impacts of prenatal alcohol exposure (Canada FASD Research Network [CanFASD], 2021). Another reason to not use this term is the impacts are not disabilities. They are the results of challenges faced by someone on the spectrum (of FASD). In this module, the term ‘adverse impacts’ is used.

In 1997, Streissguth & Kanter identified adverse impacts which children and adults with FASD may experience. This list is still used, and various studies have supported this description of impacts and added to them.

- Mental health issues
- Addictions
- Justice issues
- Education and employment issues
- Housing and homelessness
- Relationship and friendship issues
- Issues with sexuality
- Challenges of parenting with FASD

Due to stigma, people on the spectrum may experience the impacts listed above as well as challenges with independence (Flannigan et al., 2020).

Sweden showed that people with FAS\* were more likely to have experienced:

- special education
- unemployment
- receipt of a disability pension
- higher hospital admission rates for alcohol abuse
- higher hospital rates for psychiatric disorders
- higher prescription rate for psychotropic drugs

(Rangmar et al., 2015) (\*Note - Not all countries use the term FASD as a diagnosis.)

Persons with FASD know that challenges with cognitive and mental health, and social difficulties with friends, school, and work, affect their daily lives and make them feel different from others (Domeij et al., 2018). One small survey of people with FASD showed they felt they were not well supported by the social and health systems. The impacts they identified included:

- daily challenges in the classroom
- daily challenges in the workplace
- coping with mental health issues
- memory problems
- socialization difficulties
- involvement with the justice system

(Salmon & Buetow, 2012)

Impacts change in response to age and development (Paintner et al., 2012). There is an increase in lifetime prevalence of adverse outcomes as individuals with FASD grow older (Streissguth et al., 2004). Table 9.1 highlights that the types of adverse impacts experienced change over developmental periods.

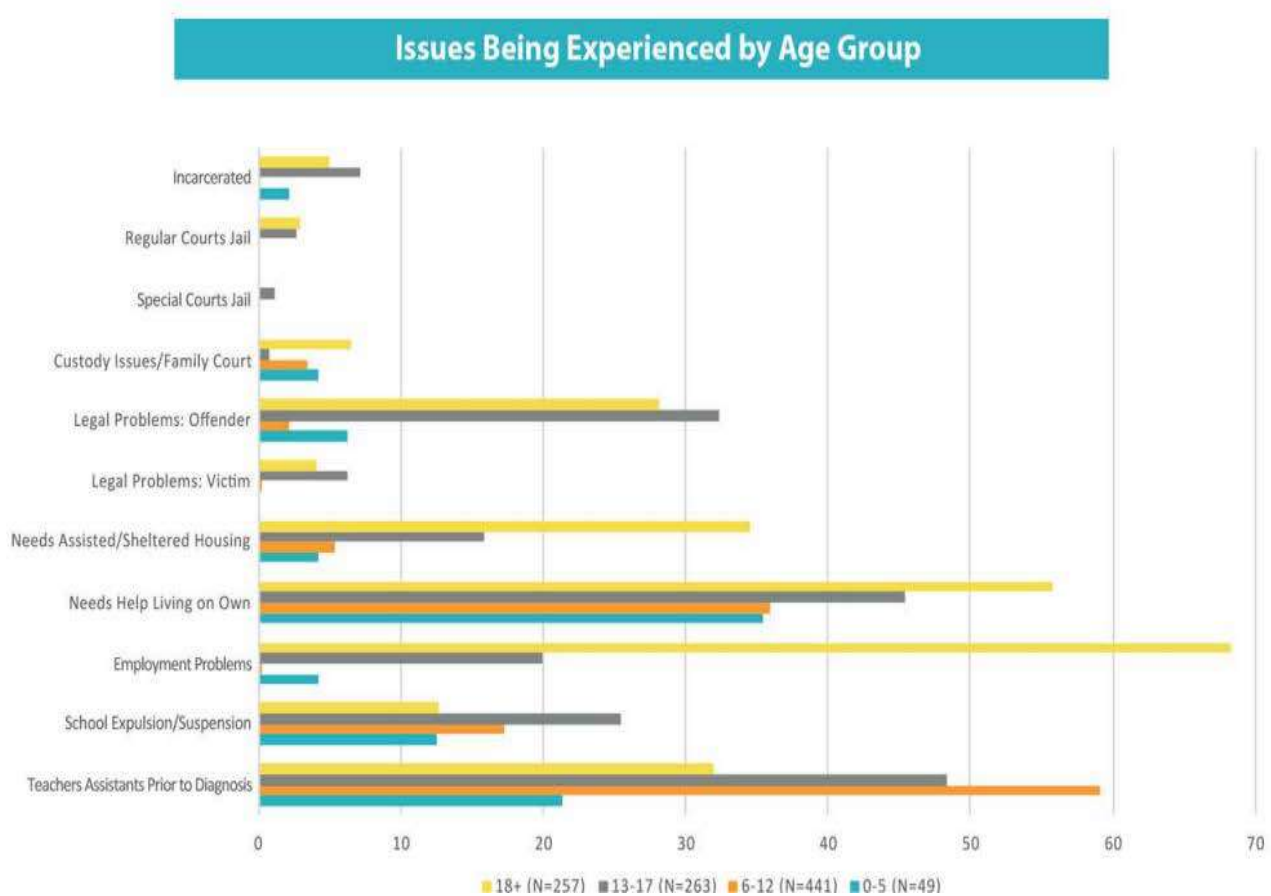
**Table 9.1 Progression of Challenges from Infancy to Young Adulthood**

Infancy/Early Childhood	Middle Childhood	Adolescence/Young Adulthood
<ul style="list-style-type: none"> <li>• Irritability</li> <li>• Insecure attachment</li> <li>• Depressive symptom</li> </ul>	<ul style="list-style-type: none"> <li>• Social problems</li> <li>• ADHD</li> <li>• Anxiety</li> <li>• Depression</li> <li>• Antisocial and disruptive behaviours/delinquency</li> <li>• Intellectual and learning difficulties</li> <li>• Psychotic disorders</li> <li>• Bipolar disorder</li> </ul>	<ul style="list-style-type: none"> <li>• Suicide thoughts/attempts</li> <li>• Alcohol misuse</li> <li>• Depressive, anxiety, and psychotic disorders</li> <li>• Aggression</li> <li>• Antisocial personality</li> </ul>

Sources: Streissguth, 2007; O'Connor & Paley, 2009; Weyrauch et al., 2017

Figure 9.1 provides information on adverse experiences of people with FASD whose records are in the Canadian FASD Database.

**Figure 9.1 Issues Being Experienced by Age Group**



Source: Canada FASD Research Network. The National FASD Database: 2019 Annual Report (CanFASD 2020, p. 12)

People with FASD can be and are successful. For example, CanFASD has created the Adult FASD Expert Collaboration Team (AFECT) to provide input on research. Members of the team are on the spectrum.

Backgrounds include:

- parent
- advocate
- certified dog groomer
- living independently
- author
- clothing designer
- motivational speaker
- president of a non-profit BMX club
- COVID-19 screening officer
- high school graduate
- level 2 certified cook
- married

(CanFASDblog, 2021)

Many factors can make a positive difference for people with FASD and their families:

- Early intervention with mother to prevent more alcohol-exposed pregnancies<sup>1</sup>
- Interventions to prevent exposure to adverse childhood experiences (ACEs)<sup>1</sup>
- Services before, during, and after foster care placements<sup>1</sup>

- Intensive intervention before the severity of the impacts requires residential care and involvement with juvenile corrections<sup>1</sup>
- FASD awareness and prevention<sup>2</sup>
- Caregiver and community supports<sup>2</sup>
- Professional training on FASD for service providers<sup>2</sup>
- Services that are tailored for FASD across the lifespan<sup>2</sup>
- Recognizing potential of people with FASD and building on their strengths<sup>2</sup>
- Obtaining support from health care, social care, and educational systems<sup>3</sup>

(<sup>1</sup>Burd and Popova, 2019; <sup>2</sup>Flannigan et al., 2020; <sup>3</sup>Domeij et al., 2018)

Teaching adaptive skills has shown lasting results in children. Adaptive skills include:

- |                    |                      |
|--------------------|----------------------|
| • communication    | • money management   |
| • personal care    | • home care          |
| • safety           | • making friends     |
| • food preparation | • social interaction |
| • ability to work  |                      |

(Pei, et al., 2015)

Children of similar age without FASD acquire these skills from watching others. Children with an FASD learn these skills through concrete, clear instruction, and guided practice. This type of training may reduce adverse impacts (Pei, et al., 2015). It is also helpful to include parents in this training (Pei, et al., 2015).

### **Remember Strengths!**

Although there are many challenges, parents have positive feelings about their children such as “joy, pride, and devotion” (Domeij et al., 2018, p. 5).

A strength-based approach is best when supporting children and adults with FASD. A strength-based approach reminds people about their strengths and ways of coping (Rutman, 2016). More information on strength-based approaches is provided later in this module.

### **Risk Factors and Protective Factors**

Many factors interact to determine adverse impacts and extent of these impacts. These factors include individual, family, system/community, and cultural. Some factors are protective, and others are risk factors (Olson & Montague, 2011; Petrenko et al., 2019). Risk factors are conditions that increase the likelihood of the development of adverse impacts. Protective factors promote the development of competence, or adaptive functioning.

Sometimes, even with all the protective factors, someone with prenatal alcohol exposure may still experience a high degree of adverse impacts. Protective factors remain important. Protective factors can reduce the possibility of adverse outcomes (Petrenko et al., 2019).

Specific family-level risk and protective factors can include:

- parent-child interaction patterns
- caregiver's way of judging a child's level of disability
- self-efficacy/level of stress of parent
- family resource needs

(Olson et al., 2009)

At the system level, risk and protective factors for individuals with FASD include the level of awareness about FASD, as well as the availability, accessibility, and implementation of diagnostic and support services (Petrenko et al., 2013; Ryan, Bonnett, & Gass, 2006; Streissguth et al., 2004). A protective factor as children/youth get older is to plan the transition to the adult system. This can include providing appropriate, intensive supports in daily living activities (Pei et al., 2021).

Secondary behaviors are defensive behaviors that develop over time when there is a chronic "poor fit" between the person and their environment. Defensive behaviors are normal protective reactions to frustration...  
Malbin (2004, p.56)

Protective factors play a large part in creating a good fit with their environment for children, youth, and adults with FASD (Malbin, 2006). A good fit for someone is based on understanding their distinct strengths, abilities, interests, and struggles, and taking into consideration the person's primary and adverse impacts. If an ongoing poor fit is causing or increasing adverse impacts, it is worthwhile to identify this and create a good fit as early as possible. Creating a good fit takes some work, but it can lessen or eliminate adverse impacts.

### **Risk Factors for Children with FASD**

Some risk factors can have impacts that are particular to those with FASD. Some of these risk factors are discussed below.

#### Adverse Childhood Experiences (ACEs)

Early childhood experiences make a difference in a child's development and health. Adverse childhood experiences can impact that child as they develop, and into adulthood (CDC, 2020; Data Resource Centre for Child and Adolescent Health, 2016). ACEs include:

- physical abuse
- sexual abuse
- emotional abuse
- physical neglect
- emotional neglect
- a family member who is depressed or diagnosed with other mental illness
- a family member who is addicted to alcohol or another substance
- a family member who is in prison
- witnessing a mother being abused
- losing a parent to separation, divorce, or death

(Centers for Disease Control and Prevention, 2020)

Note – This module does not provide an in-depth discussion on the impacts of colonialism but acknowledges colonialism has caused major harms; traumas which have led to some of the challenges discussed here. A separate module on trauma will address the impact of colonialism.

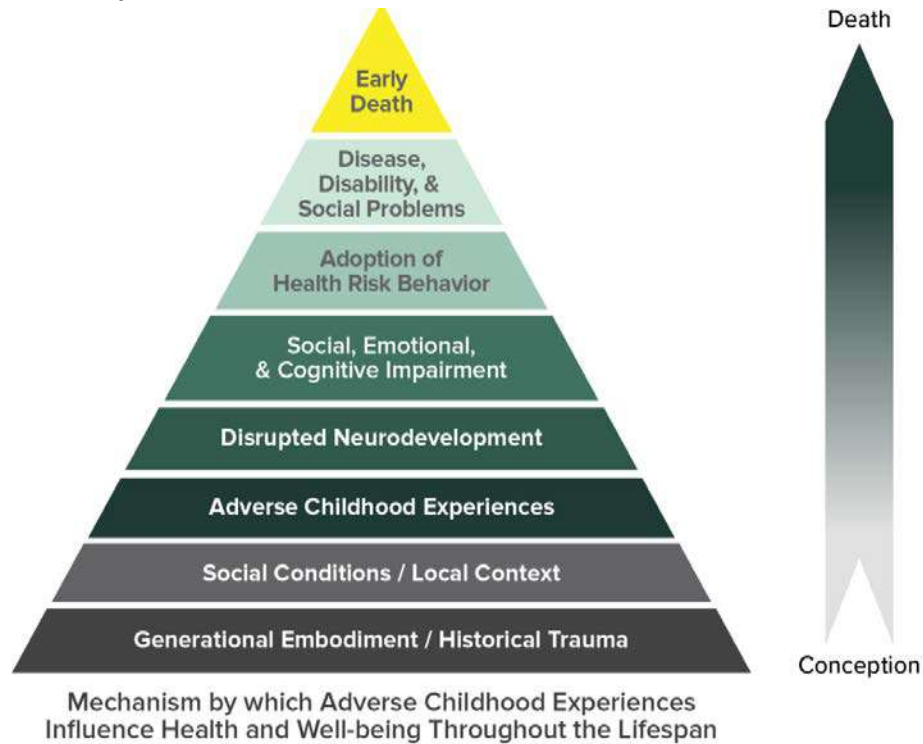
ACEs are common and can happen in any socio-economic background, culture, or country (CDC, 2020; Data Resource Centre for Child and Adolescent Health, 2016). The original study that examined ACES showed that more than half the participants had experienced one ACE (CDC, 2020; Data Resource Centre for Child and Adolescent Health, 2016). The more adverse childhood experiences a child has, the greater the chance that the child may have issues such as developmental delays, problems with school, and substance use (Centre on the Developing Child, Harvard University, n.d.). As adults with adverse childhood experiences, they may experience challenges such as:

- heart disease
- diabetes
- obesity
- depression
- substance abuse
- smoking
- poor academic achievement
- not working
- early death

(Centre on the Developing Child, Harvard University, n.d.)

Figure 9.2 shows how ACEs can affect health behaviours and health in typically developing individuals.

**Figure 9.2 The ACE Pyramid**



Source: The Ace Pyramid (Centers for Disease Control and Prevention, 2020, graphic #3)



## Prenatal Alcohol Exposure and ACEs

Children with FASD are also more likely to experience ACEs (Flannigan, McLachlan, et al., 2020; Flannigan et al., 2021; Lebel et al., 2019). In addition, children with FASD may be more sensitive to stress (Flannigan, McLachlan, et al., 2020). The combination of FASD and ACEs can lead to negative outcomes as children grow older (Flannigan, McLachlan, et al., 2020).

A review of the records of 333 children and adolescents with PAE showed high ACE scores. Almost half of the records showed four or more ACEs (Flannigan et al., 2021). People with other disabilities and the general population have lower ACE scores (Flannigan et al., 2021; Kambeitz et al., 2019). Not all individuals with PAE received an FASD diagnosis; however, there was no difference in ACE scores between those who had a diagnosis and those who did not have a diagnosis. The levels of ACEs increased with age, two or more mental health conditions, and the number of living placements. The review recommended targeted interventions to improve early caregiving situations (Flannigan et al., 2021).

One study of children with FASD and ACEs showed there was a greater chance of them developing comorbid disorders (Kambeitz et al., 2019). It also identified two extra adverse experiences that children with FASD may experience: placement in foster care and residential care (Kambeitz et al., 2019).

Preventing ACEs can reduce the risk of certain disorders. The most common co-occurring neurodevelopmental disorders in this study were:

- ADHD (85.7%)
- oral comprehension challenges (75.5%)
- sleep disturbance (63.3%)
- cognitive impairment (IQ < 85) (61.2%)
- visual impairment (53.1%)

(Kambeitz et al., 2019)

The negative impacts of prenatal alcohol exposure and ACEs may be reduced by:

- providing stable, supportive relationships and environments
  - providing early interventions
  - using trauma-informed practices
  - developing system-level strategies to reduce ACEs
- (Flannigan, McLachlan, et al., 2020)

Neurodevelopmental disorders are a group of conditions that start early in development and are characterized by developmental differences that often produce impairments of personal, social, academic, or occupational functioning. The range of developmental challenges varies from very specific learning difficulties to global impairments of social skills or cognition. Examples of neurodevelopmental disorders include attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), obsessive compulsive disorder (OCD), intellectual disability (ID), Rett syndrome, Tourette syndrome, fragile X syndrome, and Down syndrome.

Ontario Brain Institute. (2018, p. 6).

Since children with FASD are more vulnerable to stress, it is best to provide early supports and services. The supports should be holistic, focused on the family, and provided long term (Flannigan, McLachlan, et al., 2020). Providing early intervention for children with FASD is also important because the central

nervous system (CNS) function, which is impacted by prenatal alcohol exposure, can improve in early childhood (Olson et al., 2007).

Since many children with prenatal alcohol exposure also have adverse experiences after birth, it can cause problems with development, behaviour, learning, and mental health (Lebel et al., 2019). Looking at the many negative impacts a child experiences before and after birth would help with research, assessments, useful interventions, and making sure good policies are in place to help (Lebel et al., 2019).

### No Diagnosis or Misdiagnosis

Even though FASD is common, it is often not diagnosed, or it is misdiagnosed. Because of this, individuals may be given interventions or medications that do not work for them (Chasnoff et al., 2015; Morrison et al., 2019). This can cause negative impacts. It also reduces the services and support available for someone with FASD (Morrison et al., 2019). One of the most common (mis)diagnoses for children with FASD is ADHD (Chasnoff et al., 2015).

“FASD is a common disorder, which is rarely diagnosed and, as a result, nearly always treated as something else. This has consequences that are devastating for people with FASD and their families.”

Burd and Popova (2019, p. 1)

The lack of diagnosis or a misdiagnosis may happen because:

- FASD is not often diagnosed by postnatal healthcare providers
- Currently FASD requires a multidisciplinary team for diagnosis
- FASD is complex because of many impacts (i.e., prematurity, growth impairments, effect on brain, victimization, exploitation, and not able to live independently)

(Burd & Popova, 2019)

There may also be a bias in diagnosis. Professionals may be more likely to diagnose children with FASD if they are in the foster care system (Bell et al., 2016). Indigenous children are more likely to be diagnosed with FASD than non-Indigenous children (Dej, 2011; Flannigan, Harding, et al., 2020; Representative for Children and Youth, 2021). According to Representative for Children and Youth, non-Indigenous children with similar behaviours have been found to be more likely to be diagnosed with autism or another disorder.

Professionals may be careful about diagnosing children with FASD because of the lack of available interventions (Bertrand & Consortium, 2009). Misdiagnosis can also happen because of the stigma around FASD (Bell et al., 2016; Elliot et al., 2006). For example, a mother may be reluctant to confirm her use of alcohol (Bell et al., 2016).

Stigma and misunderstanding can impact the lives of families and individuals with FASD (Green et al., 2016). People with FASD can experience shame, challenges accessing services, discrimination, and stereotypes (e.g., lazy, can't learn, criminal behaviour, addictions, poor behaviour) (Morrison et al., 2019). Children with FASD are seen as victims, and adults with FASD are seen as deviant (Dej, 2011). This

bias can lead to more marginalization and stigma (Bell et al., 2016). People with FASD also feel their challenges make them different from others (Domeij et al., 2018).

### **Protective Factors for Children with FASD**

Protective factors which help reduce adverse impacts of FASD include:

- receiving relevant support services
- receiving therapeutic help services
- obtaining a diagnosis of FASD
- being in a stable and nurturing home environment
- the absence of violence or maltreatment

(Streissguth et al., 1996; Streissguth et al., 2004)

### Early Diagnosis

An early diagnosis may help to reduce ACEs (Kambeitz et al., 2019) and a diagnosis before the age of six can help prevent adverse impacts (Lange et al., 2013; Streissguth et al., 2004). A diagnosis provides caregivers with a reason or explanation for behaviours and challenges they may be experiencing. It can also help set realistic expectations (Lang et al., 2013). A diagnosis at any time is beneficial (Temple et al., 2020).

### Early Interventions

When a child has an early diagnosis, the child can take part in early interventions and supports. Early interventions benefit children with FASD (Bertrand, 2009; Lang et al., 2013; Streissguth et al., 1996). The earlier the intervention, the better the outcome. For example, if children have problems with social skills in childhood, they may still have these problems as an adult if they have not received appropriate interventions to help them (Bertrand, 2009). As mentioned earlier, CNS function seems to have the potential to improve in early childhood (Olson et al., 2007). Early intervention can include teaching parents how to interact with their young children and may help young children's neurodevelopment and behaviour (Garrison et al., 2019). It may also reduce adverse childhood experiences (Kambeitz et al., 2019).

Service providers and families do the best they can (Pei et al., 2021). One of the challenges is that there is not a lot of research in the area of interventions (Domeij et al., 2018; Pei et al., 2021). Most strategies are used because experts agree that they work, even though there is not much formal research or evaluation to prove it (Pei et al., 2018). This can impact the ability to provide evidence-based supports. A lack of interventions for young people and adults can lead to a growing gap in development and possible adverse impacts (Reid et al., 2015). Hopefully, there will be more research and evaluation on successful methods of positively supporting persons with FASD.

### Providing Positive Support to Help Parents and Caregivers

Stable home environments benefit all children, in particular children with FASD, because they may be more sensitive to stress. It is important to remember that the impact of PAE on the central nervous

system may be the reason for challenging behaviours, rather than the quality of parenting. This understanding may help people who are working with the families. Supporting parents and caregivers may help to reduce the stress experienced by families (Mukherjee et al., 2019). Support may include:

- assessing home environment for stability<sup>1</sup>
- maintaining regular contact to promote stability<sup>1</sup>
- helping parents with their self-care<sup>1</sup>
- helping parents understand FASD<sup>1</sup>
- helping parents obtain respite and other help they may need<sup>1</sup>
- providing training in parenting strategies/attitudes<sup>1</sup>
- addressing attitudes and responses to behaviour<sup>1</sup>
- helping families plan for the child's future (e.g., put support plans in place for transition to adulthood)<sup>1,2</sup>

(<sup>1</sup>Pei et al., 2021; <sup>2</sup>Mukherjee et al., 2019)

### **Potential Adverse Impacts**

This section discusses potential adverse impacts of FASD.

#### Disrupted Education

Children go to school to learn and gain skills to become independent and get a job. Children with neurodevelopmental differences can find it difficult to learn in a typical classroom. This can lead to impacts such as falling behind, finding it difficult to learn and make friends, and they may avoid school or drop out. When students have the right supports, they can be successful to the best of their abilities.

There are many children with FASD in the school system. They come from all socio-economic backgrounds, educational backgrounds, and ethnicities.

FASD is more prevalent than autism spectrum disorder, down syndrome, and cerebral palsy (Flannigan et al., 2018; Popova et al., 2019) but is often not recognized. As already mentioned, many students with FASD do not have a diagnosis. They may also have comorbidities and symptoms that overlap with autism or ADHD (Pei et al., 2020). Most children with FASD do not have distinctive physical features, and educators, professionals, and families may not realize they are on the spectrum. The students can have an IQ in the typical range when tested, and they may appear as though they can learn well (Brett et al., 2018). The disability is shown through behaviours, and the students may be seen as defiant (Brett et al., 2018).

In the greater Toronto area (GTA), a study of children aged seven to nine showed a prevalence between 2% and 3% (Popova et al., 2019). None of the children diagnosed with FASD in this study had a previous diagnosis of FASD (Popova et al., 2019). The prevalence of FASD is probably higher than this number. Studies in the United States have shown a prevalence of up to 5% (May et al., 2014).

Even in the early school years, children with FASD may struggle to fit in and learn the social and academic expectations of the classroom. Many parents report high rates of dropping out of school or skipping classes once their children with FASD move into the higher grades. Research suggests that 43% of people with FASD had disrupted school experiences (Streissguth et al., 1996).

Students with FASD have complex needs. These needs are different from children with other neurodevelopmental disorders (Millar et al., 2014). No two children with FASD have the same impacts (Millar et al., 2014). It depends on which part of the brain was impacted by alcohol and when the brain was impacted by alcohol. If the disability is misdiagnosed or not recognized as FASD, they may not receive the right supports to set them up for success.

Children and young adults can have impacts in the following areas:

- Verbal comprehension<sup>1</sup>
- Comprehension<sup>1</sup>
- Perceptual reasoning<sup>1</sup>
- Working memory<sup>1</sup>
- Processing speed<sup>1</sup>
- Externalizing behaviour<sup>1</sup>
- Attention<sup>2</sup>
- Executive functioning<sup>2</sup>
- Planning demands of motor tasks and longer response time<sup>2</sup>
- Inconsistent performance (can do task one day and not the next day)<sup>2</sup>
- Problems with adaptive behaviour<sup>2</sup>
- Social communication<sup>2</sup>

(<sup>1</sup>Popova et al., 2019; <sup>2</sup>Ali et al., 2017)

It is best for students and families to receive timely interventions and supports (Popova et al., 2019). So, why doesn't this happen?

Children are usually in school when they receive a diagnosis of FASD because some of the impacts (e.g., challenges with executive function) are not noticeable until children are older (Pei et al., 2020). It can be challenging to identify children with FASD in earlier years.

An examination of scores of Canadian children in kindergarten (using Early Development Instrument) showed that many children with FASD had better developmental health than children with other neurodevelopmental disabilities (NDD) (Pei et al., 2020). The study also showed children with only FASD did better than children with FASD and comorbid diagnoses. However, more children with FASD had problems at home than children with other NDD.

Problems at home can impact learning and the supports children may need to help them learn. This is a

Intra-individual variability (IIV) is defined as systematic within-person variation in performance either across test sessions (e.g., test/retest performance on the same task) or in one session (e.g., variations in performance on multiple trials of a single task).

IIV uniquely contributes to predicting adaptive behavior above and beyond attention, while attention partially mediates the relationship between IIV and adaptive behavior. This is the first study to the authors' knowledge to show the presence of increased IIV in children with FASD. It additionally provides evidence that IIV measures some inherent variability in performance independent of poor attention in children with FASD.

Ali et al., (2017, p. 1)

double impact for children with FASD (Pei et al., 2020). Children and adults with FASD from unstable home environments are at more risk to have problems with school, the law, and substances (Streissguth et al., 2004). This reinforces the importance of supporting families, parents, and caregivers of children with FASD.

With a better understanding of FASD and the early signs of FASD in young children, earlier interventions could be implemented, and educators could anticipate the needs of children with FASD as they grow older. This would be proactive and strength-based (Pei et al., 2020). In the area of education, these practices were suggested by experts and evidence:

- Functional assessments
- Use of a unique learning profile

(Pei et al., 2018)

Children with FASD do better in elementary school than in high school. That is because of the daily consistency of teachers, classrooms, routines, and expectations. When students with FASD go to high school, the environment is different. They may constantly be changing classrooms, teachers, and routines and expectations are different (Brett et al., 2018).

When children with FASD are not understood and do not receive the right supports in school they may:

- drop out of school
- become involved with the justice system
- have mental health challenges
- develop problems with substances

(Millar et al., 2014)

There are many reasons they may not receive the right supports.

- The functional assessment and psychoeducational supports may not be useful or easily understood by teachers and Educational Assistants (EA).
- Teachers and EAs don't have training and education about FASD.
- There is not effective communication between everyone involved with the child.
- Caregivers may not be viewed as knowledgeable about FASD and their input may not be valued.
- Children are sometimes removed from classroom to work with EA so students receive less time learning from teacher and are removed from their fellow students and can experience stigma.

(Brett et al., 2018)

When children and youth leave the school system, they may be unsupervised and have a lot of unstructured time. This can lead to more challenges. Families have, over the years, become involved in advocacy within the school system. They continue to work hard to collaborate with teachers and school systems to promote educational opportunities that work for a more diverse group of students. School systems recognize the need for information and increased awareness and understanding of FASD to improve the success of children in the school system. Students benefit from the presence of an EA, a modified classroom, and a variety of learning accommodations (Healthy Child Manitoba, 2018).



The Fetal Alcohol Spectrum Disorder Ontario Network of Expertise (FASDONE) (2014) provided this information in Figure 9.3 to help set children with FASD up for success.

Figure 9.3 Starting Points for Educators

- ✓ All students with FASD have strengths. Build on their individual strengths rather than focus on deficits.
- ✓ All staff and volunteers at school and in after school programming need to have ongoing and consistent FASD training in order to understand these children differently and operationalize successful interventions.
- ✓ Adjust expectations for students with FASD to create a “good fit”. All will need a variety of accommodations and some may require modifications. Individual Education Plans (IEPs) should reflect a student’s individuality.
- ✓ Adaptive functioning assessments, ideally the Vineland, are much more reflective of the student’s true abilities. IQ scores are not a good indicator of the student’s useable intelligence, strengths or abilities.
- ✓ Remember, their brains work, but differently from what is seen as “normal”. A student’s learning difficulties are NOT a reflection of your skills as an educator.
- ✓ Dysmaturity means social and emotional development is often half their chronological age (e.g., developmentally 6 at 12 years of age). Adaptive functioning assessments, eg. the Vineland, clarify students’ actual developmental level of ability and are important for understanding their brain-based behaviours.
- ✓ Students with FASD all have good and bad days – a good day does not mean they have mastered a skill.
- ✓ Activities based on a student’s strengths should always be available. Withholding them is not instructive.
- ✓ Understanding all aspects of a child’s functioning helps clarify behaviors. Neuropsychologists, Occupational Therapists, and Speech-Language Pathologists are important neurobehavioural team members.
- ✓ Some students with FASD may do well in an integrated classroom with on-going support.
- ✓ Evaluate environments for sensory input. Children are often easily overstimulated and slow to settle. The less “incoming data” the better for students with FASD. Provide non-punitive quiet areas.
- ✓ A student with FASD needs one or two “go-to” adults in the school who understand FASD well for when they are overwhelmed, exhausted or need a break. Ensure at least one adult is always available.
- ✓ A student with FASD who genuinely feels liked, safe and welcome at school will be more successful.
- ✓ Provide ongoing support. Start accommodations without a diagnosis. If it looks like FASD, it probably is – Think FASD First. This is brain-based behaviour. Providing effective FASD supports will not harm any student.
- ✓ These are students with a disability; think they *can’t*, not they *won’t* (Diane Malbin).
- ✓ Always use person-first and respectful language. These are students with FASD not FASD students/kids.
- ✓ FASD is a permanent, physical disability that you can’t fix but a condition which you can significantly help with continued, consistent and appropriate or “good fit” supports.
- ✓ Think of appropriate supports as a wheelchair for the brain, a wheelchair that will always be needed. Therefore, focus on building interdependence for life, not independence after graduation.
- ✓ Regression will take place if supports are removed. This is a life-long disability. Supports must remain.
- ✓ Parents and caregivers of children with FASD are usually experts and must be equal members of your school team supporting students with FASD (and other neurobehavioural disorders).

Source: Education Essentials for Students With FASD: Setting Them Up For Success (Fetal Alcohol Spectrum Disorder Ontario Network of Expertise [FASDONE], 2014, p. 1)

### *Education in Saskatchewan*

In partnership with stakeholders, the Ministry of Education continues to actualize a needs-based model of identifying and providing support for students. This is intended to ensure that:

- all students, including those with needs related to FASD, are provided with supports that enable them to develop and attain competencies and independence
- all students have access to appropriate learning opportunities, resources, and supports
- all students are supported through differentiated and responsive instruction
- all students are provided with inclusive opportunities to reach their potential

Funding for FASD programs is provided by several ministries, including the Ministry of Health and the Ministry of Social Services. This funding:

- supports FASD prevention initiatives, such as public wellness promotion campaigns, workshops, and FASD awareness and prevention initiatives specifically targeting youth
- increases access to adult assessment and diagnostic services
- supports individuals living with FASD by providing access to FASD community supports

The Supports for Learning (SFL) subcomponent of the funding model allocates funding to boards of education for the salary costs (i.e., for teachers, professionals, and paraprofessionals who provide services and programming to ensure that all students, including students with FASD, have equal access to, and benefit from, the provincial education program in an inclusive setting) and non-salary costs (e.g., assistive technology) related to supports required for learning (Lynn Harper Harris, Ministry of Education, personal correspondence, 2021).

These resources were recommended by an issue paper by Brett et al., (2018) to support students with FASD:

*Engaging All Learners! Supporting Students with Fetal Alcohol Spectrum Disorders*  
<http://www.engagingalllearners.ca/il/supporting-students-with-fasd/>

*What Educators Need to Know about FASD*  
[https://www.gov.mb.ca/healthychild/fasd/fasdeducators\\_en.pdf](https://www.gov.mb.ca/healthychild/fasd/fasdeducators_en.pdf)

*Understanding FASD: A Comprehensive Guide for Pre-K – 8 Educators*  
[https://sites.duke.edu/fasd/files/2016/04/FASD\\_Guide.pdf](https://sites.duke.edu/fasd/files/2016/04/FASD_Guide.pdf)

*Teaching Students with FASD: Building Strengths, Creating Hope*  
<https://education.alberta.ca/media/385139/teaching-students-with-fasd-2004.pdf>

*Making a Difference: Working with Students who have FASDs*  
[http://www.education.gov.yk.ca/pdf/publications/fasd\\_manual\\_2007.pdf](http://www.education.gov.yk.ca/pdf/publications/fasd_manual_2007.pdf)

*POPFASD, the Provincial Outreach Program for FASD*  
<https://www.fasdoutreach.ca/>

### Health Impacts

Most people think of FASD as a brain-based impact of prenatal alcohol exposure. In fact, FASD is a whole-body disorder with physical and brain-based effects. Awareness that FASD is a whole-body disorder would be useful for people in the medical and mental health field (Mela et al., 2019).

Some research has shown that people with FASD are more likely to be hospitalized (Oh et al., 2020) and may not live as long as neurotypical people (Thanh & Jonsson, 2016). One study identified 428 co-morbid conditions with FASD (Popova et al., 2016). Co-morbid conditions may not be an adverse impact of FASD but do affect the individual. Co-morbid conditions also contribute to significant healthcare costs. They may also impact how a person presents and responds to a mental health condition (Mela et al., 2019). The health impacts may be primary, but the challenges related to FASD may lead to challenges identifying these health issues or they may become chronic.

Caregivers of children reported these common diagnoses:



- Eye conditions
- Asthma
- (Reid et al., 2021)
- Heart conditions
- Skin problem

Myles Himmelreich, C. J. Lutke, and Emily Travis Hargrove conducted a survey about the physical health of people with a confirmed diagnosis of FASD. Myles, C. J., and Emily have FASD, and they also have multiple physical health challenges. People with FASD reported a higher rate of physical health challenges than the general population. These health issues also developed at earlier ages. They identified PAE causes 'long-term vulnerability to disease' (p. 291). When health practitioners watch for health concerns, treatment can begin earlier and perhaps prevent the progression of health issues (Himmelreich et al., 2020). Health impacts were found in the following:

- Congenital disorders (e.g., cleft palate)
- Growth
- Organ systems
- Dental and oral health
- (Himmelreich et al., 2020)
- Vision and hearing
- Sleep
- Mental health and substance use

A concern Himmelreich et al. (2020) identified is that many people with FASD may feel pain differently. They may also need assistance with getting and using medication. Many individuals with an FASD may need help to get medical services or do not use health services (Pei et al., 2015). Mentors or support workers could help them access health services and follow-up services (Pei et al., 2015). Some case studies show children have secondary medical challenges such as middle ear infections and upper respiratory problems because of autoimmune impacts (Noor & Milligan, 2018).

A study in Korea showed causes of death for people with FASD included:

- diseases of the nervous and respiratory systems
- diseases of the digestive system
- congenital malformations
- mental and behavioural disorders
- diseases of the circulatory system
- (Oh et al., 2020)

Health impacts include:

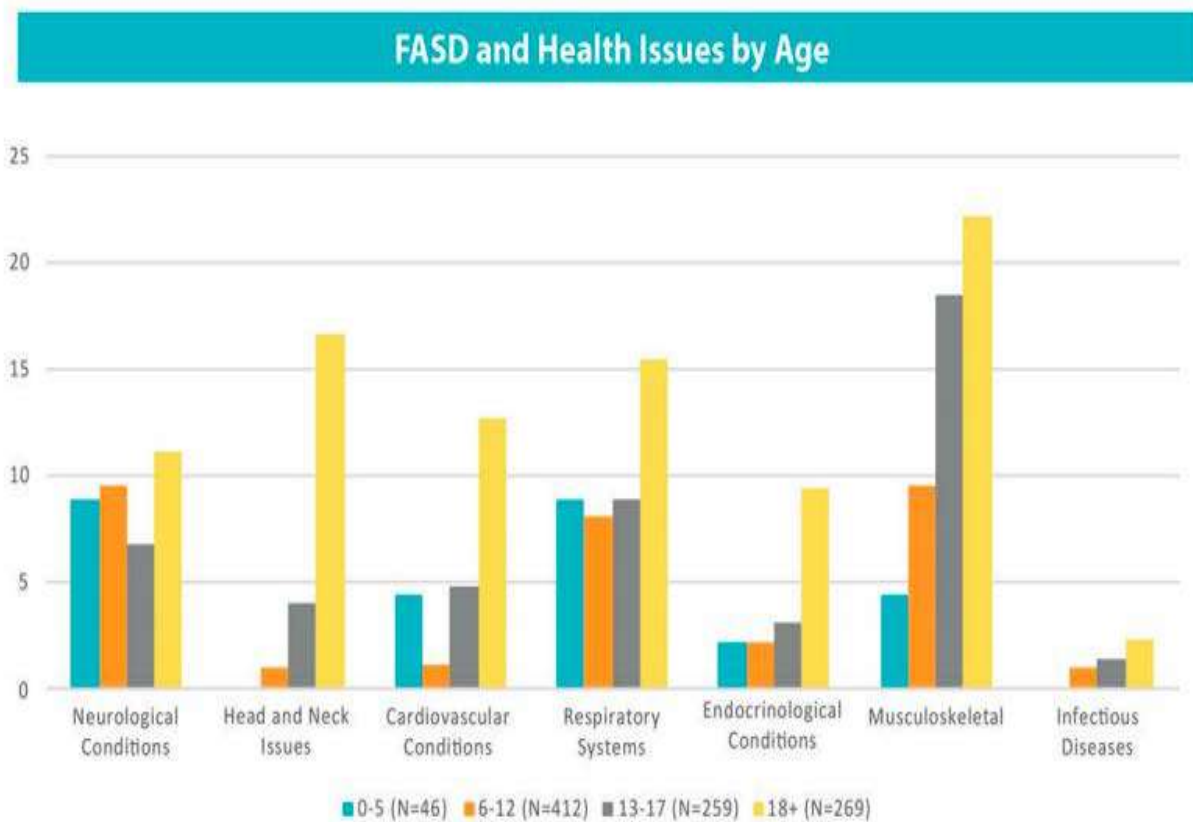
- nutritional deficits
- sleep disorders
- seizures
- immune system impacts
- elimination problems
- dental health concerns

These can contribute to potential adverse outcomes (Pei et al., 2021).

A 'whole body' perspective, including brain and body function, is useful when thinking about impacts to daily functioning for people on the spectrum (Mela et al., 2019; Pei et al., 2021).

Figure 9.4 provides information on the health issues of people with FASD in Canada whose records are in the National FASD Database.

**Figure 9.4 FASD and Health Issues by Age**



Source: The National FASD Database 2019 Annual Report (CanFASD, 2020, p. 15)

In the area of health guiding practices over the lifespan of people on the spectrum, expert consensus and evidence suggest:

- preventative mental health services
- supported access to medical care
- supported recreational activity
- management of sexually exploitive situations and risky behaviour

(Pei et al., 2021, p. 5)

### Mental Health/Wellness Issues

Fostering stability and nurturing skills and abilities that contribute to mental well-being through all developmental stages may improve long-term outcomes for people with FASD. When people with FASD are not supported in the right way or do not receive supports, they may be more likely to have



mental health challenges and substance use difficulties (CanFASD, 2021). Targeted and individualized FASD-informed interventions can be helpful (CanFASD, 2021; CanFASDBlog, 2020). More research is needed in this area (CanFASD, 2021).

Caregivers, researchers, and service providers see an association between PAE and mental health (O'Connor & Paley, 2009). When it comes to mental health, a lifespan approach is important (Flannigan et al., 2020). This provides opportunities to adapt interventions that can strengthen experiences, skills, and support systems that bring about mental wellness. This can improve long-term outcomes for people with FASD (Flannigan et al., 2020). Providing strong support includes considering the person's social and adaptive needs and their cognitive ability (Pei et al., 2021). Understanding FASD, adapting treatment to the individual's needs, and using a strength-based approach is important for mental health professionals working with someone with FASD (Mela et al., 2019). Having realistic expectations and highlighting successes are important.

When people with FASD are not supported, they may be more likely to experience high rates of mental health and substance use difficulties (CanFASD, 2021). They are more likely to have mental health issues than people in the general population (Anderson et al., 2018; Streissguth et al., 1996). About 90% of people with FASD have a mental health diagnosis (Pei et al., 2011; Streissguth et al., 1996). This can happen because of the neurological and cognitive impairments associated with FASD (O'Connor & Paley, 2009).

Mental health challenges (e.g., anxiety, depression) may have a neurobiological basis (Hellemans et al., 2010). Mental health problems that appear in childhood do not disappear as someone ages. They may be a basis for the development of other challenges as a child ages to adulthood (Pei et al., 2011).

People with FASD may be more likely to have these mental health impacts than other people:

- Attention deficit hyperactivity disorder<sup>1,4</sup>
- Intellectual disability<sup>1</sup>
- Oppositional defiant disorder<sup>1</sup>
- Depression<sup>1,4</sup>
- Psychotic disorder<sup>1</sup>
- Bipolar disorder<sup>1</sup>
- Post traumatic stress disorder<sup>1</sup>
- Obsessive compulsive disorder<sup>1</sup>
- Anxiety<sup>2,4</sup>
- Reactive attachment disorder<sup>1</sup>
- Greater risk of death by suicide<sup>2</sup>
- Greater risk of alcohol and drug use<sup>2</sup>
- Impact of environment and PAE<sup>2</sup>
- Panic attacks<sup>3,4</sup>
- Auditory and visual hallucinations<sup>3</sup>
- Suicidal threats and attempts<sup>4</sup>

(<sup>1</sup>Weyrauch et al., 2017; <sup>2</sup>Pei et al., 2011; <sup>3</sup>Gibbard et al., 2003; <sup>4</sup>Streissguth & O'Malley, 1997)

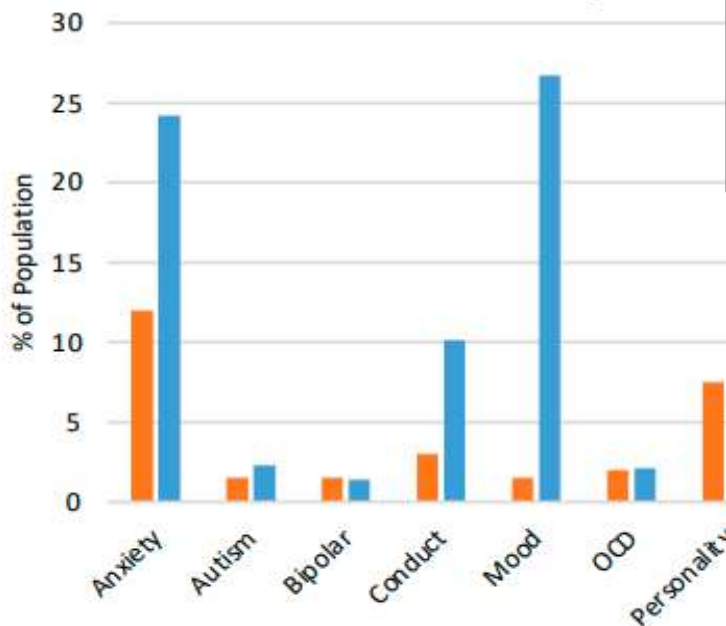
In 2020-2021, COVID-19 impacted the health of people with FASD beyond the impacts other Canadians may have been experiencing. Problems included:

- refilling prescription
- getting an appointment to see a healthcare provider
- getting transportation to appointments
- taking part in virtual appointments because of a lack of phone or internet

(McFarlane, 2021)

Figure 9.5 reinforces the research that people with FASD have more mental health impacts.

**Figure 9.5 Mental Health Comorbidities in Individuals with FASD vs General Population in Canada from the Canada FASD Database**



The neurobehavioural disorder associated with prenatal alcohol exposure (ND-PAE) is now included in the Diagnostic and Statistical Manual 5 (DSM 5) of American Psychiatric Association (APA), 2013 as a condition for further study and a new psychiatric diagnosis (Hagen et al., 2016). ND-PAE includes the behavioural, developmental, and mental health aspects of FASD (Hagan et al., 2016; National Institute on Alcohol Abuse and alcoholism [NIAAA], 2020).

Source: The National FASD Database Newsletter (Cook et al., 2020, p. 1)

Mental health impacts a person’s overall health, substance use, lifespan, homelessness, parenting, and other aspects of participating in society. It can have an impact on the social, school, and work-life of people with FASD (Pei et al., 2016).

When the Canadian diagnostic guidelines were updated in 2015, affect regulation (AR) was added as one of the 10 domains examined for diagnosis (Cook et al., 2016). Affect regulation is how one controls emotions, reacts to stress, and reacts to different situations. A study of the Canada FASD Database (which

Mental health problems have historically been described as ‘secondary disabilities’ that happen because of the interaction between primary disabilities and the environment (Pei et al., 2011). Mental health impacts are now understood to result from a complex interplay between multiple biological factors and various environmental factors. The recommended term for what was previously called ‘secondary disabilities’ is now ‘adverse outcomes or impacts’. This change in terminology is an attempt to dispel the belief that these difficulties are less important than the primary brain and body deficits experienced (Hellemans et al., 2010; Pei et al., 2011; Canada FASD Research Network [CanFASD], 2021).

collects information from a variety of diagnostic clinics in Canada) showed that affect regulation impairment is associated with multiple mental health diagnoses in those with FASD (Temple et al., 2019).

People with affect regulation (AR) issues when diagnosed with FASD were more likely to have:

- conduct disorder
- attachment disorder
- post traumatic stress disorder
- history of suicidality

(Temple et al., 2019)

Mental health providers should know about FASD, understand FASD, and help reduce the stigma related to FASD (Mela et al., 2019). Unfortunately, many mental health professionals are not educated about FASD (Anderson et al., 2017). Mental health for people with FASD is also not included in Canada's mental health strategy (Anderson et al., 2017).

### *Children and Mental Health Challenges*

When there is PAE, this can impact the development of the stress response system in a fetus; changing typical pathways, and therefore the way the brain responds to stress (Green & Salmon, 2015). In addition, exposure to stress, in utero or early life, can also impact the developing stress response system (Green & Salmon, 2015). When PAE is experienced in addition to prenatal and/or postnatal stress, the impact on the child's stress-response system is compounded, increasing the risk of future mental health issues (Green & Salmon, 2015). The impact on the brain of males may be different, increasing the risk for males to experience difficulties related to their stress response system (Green & Salmon, 2015).

Infants with PAE can show signs of central nervous system impacts such as:

- jitteriness
- irritability
- autonomic instability
- slow adaptation
- low levels of arousal
- increased levels of activity
- troubles with sleep patterns

(O'Connor & Paley, 2009)

These impacts continue throughout childhood and are associated with higher levels of psychological dysfunction throughout the lifespan (O'Connor & Paley, 2009).

It has been suggested that children prenatally exposed to alcohol are more likely to perceive (see) confusing peer behaviours as hostile and respond aggressively. Because of poor affect and behavioural regulation, they are more likely to act on their aggressive impulse. This adds to the development of disruptive disorders and reckless behaviours (O'Connor & Paley, 2009).

Every child with FASD is different. Many children with FASD have some mental health challenges. Some of the mental health challenges are:

- intellectual disability
- sleep abnormalities

- reactive attachment disorder
- anxiety
- posttraumatic stress disorder
- oppositional defiant disorder
- language disorder
- learning disability
- depression
- bipolar disorder
- some features of autism
- certain phobias

(Hagan et al., 2016)

Between 50% to 90% of children with FASD also have a diagnosis of attention deficit hyperactivity disorder (ADHD) and/or attention deficit disorder (ADD). Many children are diagnosed with ADHD before they are diagnosed with FASD. Children with FASD may have a different ADHD than the typical ADHD. Typical treatments, including medications, may not work (Pei et al., 2011).

Obtaining a diagnosis of FASD when younger and having professionals screen for mental health challenges could be a protective factor for people on the spectrum (Pei et al., 2011). Children could be taught coping strategies and interventions could be used to help them as they age (Temple et al., 2019). Unfortunately, children are often diagnosed with mental health disorders before they are diagnosed with FASD (Temple et al., 2019).

An example of a successful school-based strategy was a holistic mental health program to build resiliency in students. It built mental health literacy and taught dialectical behaviour therapy (DBT) strategies (Katz et al., 2020). Participants included a large group of students with various neurodevelopmental disabilities. All participants showed improvements in self-concept, coping skills, and social support. These improvements continued through the school year (Flannigan et al., 2020).

Since children with PAE are more sensitive to stress and are more likely to experience it, supports to help them deal with stress are beneficial and important (Flannigan et al., 2020). The problems these children have do not disappear as they get older. A child's PAE related problems may cause other mental health issues as they grow older (Pei et al., 2011). In fact, 70% to 90% of people with FASD have mental health challenges by adulthood (Temple et al., 2019). Individuals with FASD may have better mental health outcomes if they are connected with mental healthcare providers when young (Flannigan et al., 2019). A literature review noted that problems that appear when children are young may show a "convergence of genetic, environmental, and neurophysiological factors that persist into adulthood" (Pei et al., 2011 p. 438).

An interesting observation is that children and adults with 'FASD with sentinel facial features' (formerly called Fetal Alcohol Syndrome) are not as likely to have problems with conduct disorder than people with PAE (without identifiable facial features) (Pei et al., 2011). That might happen because people with FASD with sentinel facial features may receive more supports.

### **The Importance of Remembering Strengths and Using FASD Informed Approaches**

Children and adults on the spectrum have many strengths and abilities. People on the spectrum are resilient (Flannigan et al., 2018). Remembering the strengths and using an FASD informed approach can make it easier to support children and people on the spectrum to be their best. This can help reduce adverse impacts.

Each person with FASD is different, and strategies and supports are best when individualized and adapted for the needs of the individual. For example, someone’s chronological age may not match the developmental stage. Someone may be doing the best they can at their stage of development. Providing developmental-stage-appropriate supports that recognize an individual’s social and cognitive capabilities make a difference (Pei et al., 2018).

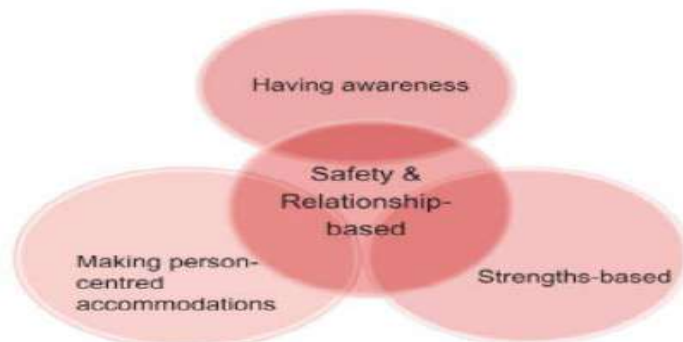
### FASD Informed Approaches

An FASD informed approach includes:

- knowledge about the impacts of PAE
- understanding there may have been experiences of violence, victimization, abuse, or trauma
- accepting brain-based differences may make it harder to follow program rules
- understanding behaviour may be due to brain-based differences
- understanding someone may have experienced poor social determinants of health (e.g., poverty, homelessness, not completing school, early life adversity)
- acceptance that system, program, and/or service providers need to make changes - not the person (Rutman, 2016)

Rutman (2016) suggests the following principles for an FASD informed approach.

**Figure 9.6. FASD Informed Framework**



Source: Becoming FASD Informed: Strengthening Practice and Programs Working with Women with FASD (Rutman, 2016, p.16)

Without recognizing the impacts of prenatal alcohol exposure and the importance of FASD informed supports, people with FASD do not receive the appropriate supports and experience misperceptions which can set them up for negative life experiences.

“... treatment and parenting approaches, our education system, our child welfare approaches, and our justice approaches are based on receptive language processing. If we fail to diagnose FASD because we are not paying attention or because the symptoms are similar to other mental health disorders, we provide the wrong treatment and we get the wrong outcomes. We consistently set people up to fail because we are not recognizing this. We use our ‘evidence-based practices,’ such as motivational interviewing and cognitive-behavioural therapy techniques. However, these are based on receptive language processing, which means that they are not going to be the most effective techniques for someone with FASD. And when the techniques do not work, we say that the person is not motivated for treatment or is not ready for sobriety”.

Dan Dubovsky, 2009, p. 68

A good way to support people with FASD and mental health challenges is to remember the impact of prenatal alcohol exposure and use an FASD informed approach (Anderson et al., 2018; Rutman et al., 2014). Unfortunately, most people working in the mental health field do not have training about FASD (Anderson et al., 2018). They may not recognize the impact of prenatal alcohol exposure on the person. This means the supports and interventions they use may not work well for someone with FASD (Anderson et al., 2018). As well, if someone with FASD is not diagnosed or misdiagnosed, there will not be an understanding of the impacts of FASD and other comorbidities (Anderson et al., 2018). When people with FASD are not appropriately treated, they may end up in the justice system (Anderson et al., 2018). This is discussed more in the section on the justice system.

FASD is lifelong, providing early and ongoing interventions can make a difference (Flannigan, Coons-Harding, et al., 2020). Counselling, support groups, and mental health professionals can be helpful. Interventions at any time in life can benefit people with FASD (Flannigan et al., 2020). Many professionals do not see the relationship between FASD and mental health (Fast & Conry, 2011). Medical schools and training in psychiatric programs have little or no education about FASD (Anderson et al., 2017). Knowledge of FASD can help the counsellor, psychologist, or group facilitator to make changes in their practice or approach. This can improve the experience for an individual with a cognitive disability such as FASD.

Traditional methods of treatment may not work with people who have been impacted by prenatal alcohol use. That happens because people with FASD:

- may not understand the information
- may have trouble following directions and they may find it hard to take what they learn in one place and apply it in another place

(CanFASDblog, 2020)

However, people with FASD can be helped with their mental health. Interventions for FASD tend to be preventative to avoid the start of mental health challenges, stop further harm, and help with symptoms, functioning, and better quality of life (Flannigan, Coons-Harding, et al., 2020). This includes regular access to mental health and substance abuse programming, and mentorship programs for adults (Pei et al., 2015).

Hands-on tools and techniques that use all senses can be useful (Pei et al., 2015). CanFASD provides these suggestions to help:

- Use clear, direct statements and step-by-step directions to avoid confusion
- Use repetition to make sure the person remembers the information
- Think about sensory processing issues when developing treatment plans
- Practice in stable environments with minimal change to minimize anxiety
- Provide resources to improve their skills in organization and time management to make it easier to do everyday activities



(CanFASD, 2020)

Psychiatry has a role in treating patients with FASD across the lifespan (Mela et al., 2018). It ranges from support before and after birth, in infancy, early childhood, adolescence, and adulthood. Psychiatry also has a role with:

- psychology
- learning disability specialists
- adult psychiatry
- consultation liaison psychiatry
- addictions
- forensics
- geriatrics

(Mela et al., 2018)

### Medications

Psychotropic medications are often prescribed for people with FASD (Mela et al., 2018). People with FASD may not respond to medications in the same way as neurotypical people. Families have worried that healthcare providers prescribe too many medications, and the medications may not always work as expected (Mela et al., 2018). The use of psychotropic medications is not recommended for children under the age of six (Mela et al., 2018).

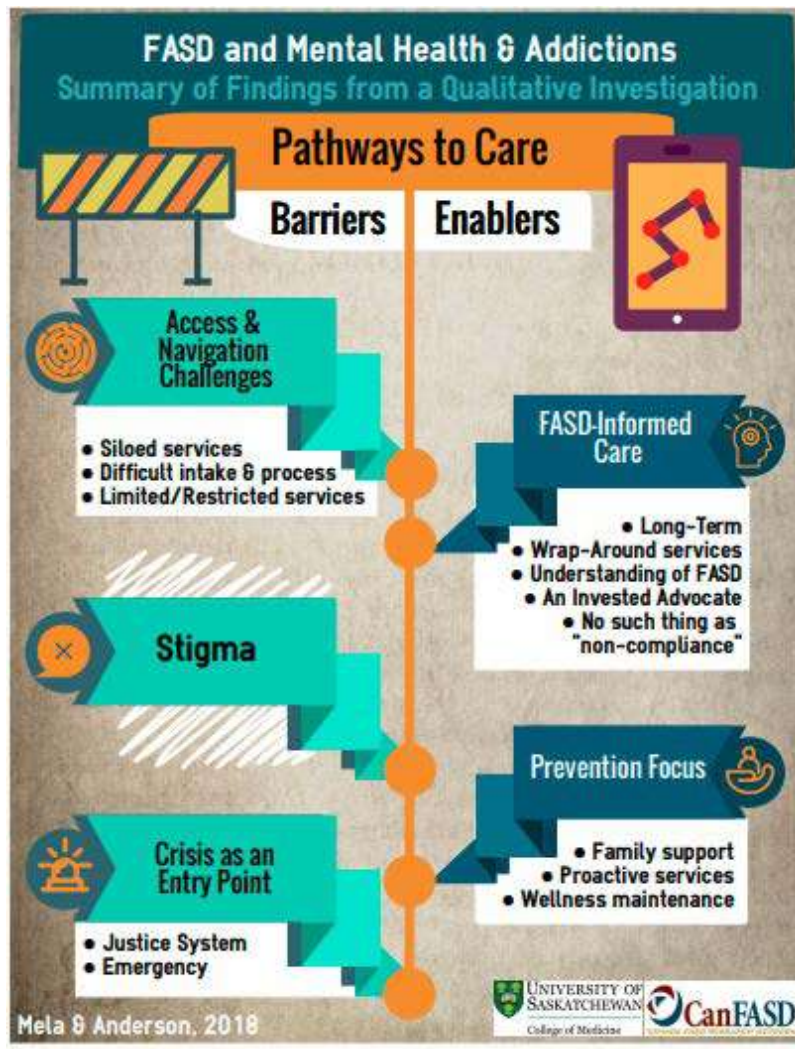
A review of literature on PAE/FASD, adversity, and stress, made these recommendations.

- Early intervention can improve outcomes for individuals with PAE/FASD, including those who experience childhood adversity.
- Service providers should consider how experiences of adversity, stress, and instability can complicate the clinical picture for individuals with PAE/FASD and employ a trauma-informed approach in their work.
- More research is needed on the co-occurrence and interaction of PAE/FASD and adversity.
- There is a need for more research to identify protective factors for individuals with FASD.

(Flannigan et al., 2020)

Figure 9.7 shows barriers and enablers to care for persons with FASD with mental health and substance use issues.

### **Figure 9.7 FASD and Mental Health & Addictions: Summary of Findings from a Qualitative Investigation**



Source: FASD and Mental Health and Addictions: Summary of findings from a qualitative investigation [Infographic] (Mela & Anderson, 2018)

### Life Expectancy

People with FASD are at risk for many things that can impact their health and safety. Children and adults with FASD have many health and mental health challenges. They can experience difficulties throughout their lives. They may have unhealthy and unsafe experiences (Badry & Marcellus, 2020). If they have access to FASD-informed supports in the early years, healthcare, and mental health care, it can make a positive difference (CanFASD, 2021).

Decisions made in the early years of life for a child with FASD can impact the outcome for the child throughout their life (Badry & Marcellus, 2020). Many children with prenatal substance exposure and/or prenatal alcohol exposure are placed in the child welfare system. A ten-year examination of Child and Youth Advocate reports of deaths or serious injury of children in care found that FASD was either

diagnosed or suspected in 16% of cases (Badry & Marcellus, 2020). The following causes of serious injuries or death among children in the child welfare system:

- suicide
- child abuse and neglect
- high risk behaviour, particularly as adolescents

(Badry & Marcellus, 2020)

The highest risk periods for death in the child welfare system were:

- birth to age 4 years
- 13 – 17 years

(Badry & Marcellus, 2020)

The report also identified reasons for why this may happen:

- Challenges to stability and permanency for children in care
- Lack of FASD-informed service provision
- The presence of concurrent mental health concerns

(Badry & Marcellus, 2020)

There is limited research on life expectancy. One study of records in Alberta showed the life expectancy of people with FAS was 34 years, which is less than half of the life expectancy of most people. This study cannot necessarily be generalized to all people with FASD (CanFASD, 2021). The study is informative because it did show that almost half of the deaths might have been prevented. Once again, appropriate, FASD-informed, individualized supports could have made a difference. The causes of death were:

- suicide
- accidents
- poisoning by illegal drugs or alcohol

(Thanh & Jonsson, 2016)

Death by suicide is a particularly concerning and serious issue for individuals, families, and professionals. People on the spectrum have a higher risk of dying by suicide than the general public. Even children with FASD have made attempts to die. Some recent studies report that adolescents with FASD are much more likely to make a serious suicide attempt compared to other teens of the same age group (O'Connor et al., 2019).

Teens with FASD who have a higher number of home placements are more likely to report thoughts of suicide or significant attempts, compared to teens with fewer placements (O'Connor et al., 2019). The risk for males with FASD was significantly greater than that of neurotypical teens (O'Connor et al., 2019). Over 30% of youth and adolescents with FASD in one study reported thoughts of suicide or had made a suicide attempt (Burns et al., 2020). Reasons for attempts included problems in self-regulation, executive function, social isolation, and other disorders (O'Connor et al., 2019).

Reasons for thinking about suicide or dying by suicide have included:

- money problems
- little social support
- depression
- being impulsive
- having a history of trauma

(Pei et al., 2011)

Providing mental health services, starting in the early years, may lead to better outcomes (Pei et al., 2011). Involving parents in treatment has a positive impact (O'Connor et al., 2019). An integrated approach to providing mental health care that is FASD informed also leads to better outcomes (Anderson et al., 2017). A beneficial strategy for young people is Safe Alternatives for Teens and Youths (SAFETY) (O'Connor et al., 2019). SAFETY helps strengthen protective supports in the family and builds skills for less harmful behaviours and lowered reactions to stress (O'Connor et al., 2019).

Dirks et al. (2019) recommended that professionals who work with people with FASD should be aware of the high rates of suicide attempts and talk about suicidal thoughts with patients. They also recommended creating an 'emergency strategy' for people who have a history of thinking about, or attempting suicide, in case of acute suicidality. Non-traditional therapeutic approaches like art therapy, service dogs, and music therapy are gaining more attention and may prove to be more effective options for some clients with FASD (Gerteisen, 2008).

The research described above suggests that people on the spectrum may be more at risk of dying earlier than the general public (Thanh & Jonsson, 2016). This is not easy for people with FASD and their families to hear. When we understand the potential causes of this and act proactively to make changes, we can make a difference.

### Substance Use Disorder

Substance use disorder is considered a mental health impact. It involves a physiological or psychological dependence on a particular substance or behaviour. This uses great resources of time and energy, leaving less time and energy for more positive pursuits that can improve one's life.

When not adequately supported, people with FASD may be more likely to experience challenges with substance use (CanFASD, 2021). Studies have shown a relationship between having an alcohol use disorders and



Use the term  
**substance use disorder**  
instead of **addiction**.

FASD (Goldschmidt et al., 2018; Pei et al., 2011; Rangmar et al., 2015; Streissguth et al., 1996). This link exists after taking into account other variables such as the parents' use of alcohol. Since there are high

levels of substance use among those with FASD, supports and interventions that are FASD informed and individualized would be beneficial (CanFASD, 2021).

Drug and alcohol use is dangerous for youth and adults with FASD, and high numbers of individuals affected by prenatal alcohol exposure develop addictions. Streissguth (1996) found 35% of those over age 12 had problems with drug and alcohol use. It seems that a “combination of genetic and disability-related factors put people with FASD at high risk for substance use disorders” (Guarnera, 2009, para.16). Due to this genetic predisposition, individuals with FASD can become addicted to alcohol quite quickly. In addition, youth and adults with FASD already have brain differences and impairments in a range of cognitive functions. The combination of pre-existing impairments and the influence of alcohol on functioning makes it even harder to make good decisions and stay safe and healthy. The risks are high for individuals with FASD when under the influence of alcohol, as this can lead to criminal behaviour, victimization, violence, and disrupted relationships. Long-term use can include all of these issues plus poverty, pregnancy, poor physical health, and homelessness. For these reasons, it is best if youth and adults living with FASD can completely avoid using alcohol and illegal drugs.

Abstinence from drugs and alcohol is hard. Alcohol use is widely accepted in our culture, and drugs are readily available, making it difficult to avoid these substances. Most Canadians drink some alcohol some of the time, but in amounts that do not cause problems. People with FASD may have friends and family members that drink alcohol or use illegal drugs. They may attend events or go places where drugs and alcohol are used. Remember, individuals with FASD learn best by watching and imitating others, so they will quickly pick up behaviours of others around them. Additionally, because individuals with FASD are so readily influenced and eager to be accepted, they will want to join in with peers in risk-taking or addictive behaviours as an attempt to make and keep friends or impress others.

Many youths and adults use drugs, alcohol, or gambling to numb emotional pains and to help cope with stress, anxiety, loss, shyness, or awkwardness. Addictive behaviours or substance use take the place of other more effective and less dangerous coping skills. These activities lead to additional troubles such as financial, employment, or interpersonal problems, making it less likely that healthy skills and strategies for managing emotions will be learned and used.

Of course, not all substance use or gambling develops into an addiction. However, if an individual with FASD does develop an addiction, they, like everyone facing an addiction, will have a lifelong recovery process. There is no quick fix for addictions, and addiction treatment may be more complex and lengthier for individuals prenatally affected by alcohol. Addictive behaviours are resistant to change, and traditional treatment approaches may not be effective for individuals with FASD. Traditional treatment approaches, like the 12-Step Programs, are based on cognitive understanding, group processes, and self-reflection. These activities and programs tend to be hard for people with FASD. When it comes to treatment of addictions in individuals with FASD, professionals have begun to explore what is required and it is suggested that “failure to recognize FASD in a client can greatly complicate treatment; correspondingly, identification of FASD can help addiction professionals deliver a far more effective treatment experience” (Guarnera, 2009, para. 16). Accommodations that seem to work include "more

structure, more one-on-one time, and someone assigned to them like a big brother or big sister or a counsellor who knows about their disabilities" (Guarnera, 2009, para. 17).

### Justice Issues

Most people with FASD are not involved with the justice system (CanFASD 2021; Mela et al., 2019). Often, when people with FASD are involved with the justice system, it is because they are victims, not the ones committing the crime (CanFASD, 2021; Pei et al., 2018). There is little research on patterns of offences by people with FASD (Mela et al., 2020). It is believed that people on the spectrum are overrepresented in correctional settings (Pei et al., 2018). It is not known for sure how many people with FASD are involved in the justice system, but the rates are high (Flannigan et al., 2018). Young people with FASD are much more likely to be in jail than young people without PAE (Popova et al., 2011). Estimates of youth with FASD in the justice system range from 11.9% to 23% (FASD Justice Canada, n.d.). Although these studies have provided evidence that a disproportionate number of individuals affected by FASD are in the justice system, it remains difficult to know specifically how many.

There is no research showing that people with FASD commit more violent crimes than others (CanFASD, 2021). Unfortunately, the media often portrays FASD in a negative light and causes people to think people with FASD are more likely to be offenders (CanFASD, 2021).

As mentioned often in this module, adverse impacts can be reduced by early diagnosis and the availability and ability to use services (Pei et al., 2018). Many people may be in the justice system because the mental health system did not recognize FASD and adapt supports (Anderson et al., 2017; Mela et al., 2019). Other reasons may include impacts of adaptive function, social skills, substance use, and childhood adversity (Anderson et al., 2017).

Some individuals with FASD are friendly, well-spoken, charming, and extroverted. They may have large numbers of friends and a large social network. Though outgoing and popular, they are vulnerable to negative peer influences. They commonly get into trouble because they are attracted to negative peers and are often taken advantage of by, or victimized by, those peers they consider friends. These individuals are at-risk for gang involvement, violence, financial problems, sexual exploitation, and substance abuse. These factors can all lead to criminal involvement and legal charges.

The concept of counterfeit criminality suggests that people with disabilities may be involved in crimes for reasons other than breaking the law on purpose (Hingsburger, 2012). People with disabilities may be involved in a crime because they want to be accepted, they have been manipulated, or they have been victimized (Hingsburger, 2012).

Because of brain differences, those with FASD are especially vulnerable. They are easily convinced to do things that are unsafe or illegal. They may not recognize that they have been set up by their peers to take the blame for a crime. They may also take the blame for things they did not do as a way to please an authority figure. They may confess to crimes they did not commit, give information about events they do not remember, and they may have difficulty understanding their legal rights, including their right to



have a lawyer and their right not to incriminate themselves (Fast & Conry, 2004). Teens and adults with FASD are commonly charged with theft, property damage, and assault. Charges often stack up as youth and adults with FASD have trouble complying with court orders, thus generating additional charges. Risks of carrying out criminal behaviour or being the victim of criminal acts are greater due to a variety of primary disabilities. Individuals with FASD may:

- be impulsive and take risks
- have a poor understanding of what might happen next
- not understand which actions are dangerous or illegal
- have a poor understanding of ownership and personal boundaries
- repeat offences due to problems generalizing and learning from mistakes
- be likely to get caught due to poor planning or inability to conceal actions

There are many reasons people with FASD can become involved with the justice system. Many of these reasons are related to the other adverse impacts that can happen because of PAE. This includes primary impacts of prenatal alcohol exposure, the lack of support people with FASD and their families have received over time, and a lack of understanding about FASD (Pei et al., 2018). People who do not seem to display the obvious impacts of PAE (e.g., have the physical appearance) had more legal problems and substance use challenges (Fast & Conry, 2004; Lynch et al., 2017). That may be because people with obvious signs of the impacts of PAE may be seen as in need of services that can be protective (Lynch et al., 2017).

There are high rates of mental illness and substance use disorder in offenders with FASD (Pei et al., 2016). The impacts of mental health may also increase high-risk behaviours that can lead to being involved with the justice system (Pei et al., 2016). Negative life stresses, lack of education, and vulnerability to the environment around them were related to negative behaviours (Lynch et al., 2017).

Other reasons for justice involvement may include the following:

- No diagnosis of FASD<sup>1</sup>
- No interventions<sup>1</sup>
- Communities do not have the right supports<sup>1</sup>
- Adverse early home environment
- Lack of social support<sup>2</sup>
- Suggestible<sup>1</sup>
- Problems with executive functioning can impact judgement<sup>1</sup>
- Confabulation<sup>1</sup>
- Not understanding rights<sup>1</sup>
- Making incorrect statements when questioned by police<sup>1</sup>
- Poor decision making<sup>2</sup>
- Lack of stability in daily activities that work as protection against involvement<sup>2</sup>
- Risky behaviour and social circle<sup>2</sup>
- Displaying skills such as language that give the impression of more understanding than they have<sup>2</sup>

- Problems connecting actions and consequences<sup>2</sup>
- Manipulated<sup>2</sup>
- Not able to see risk and remove from it<sup>2</sup>
- More vulnerable to environmental influences associated with substance use and legal difficulties<sup>3</sup>
- People in corrections know about FASD but are not ready to work with someone with FASD or to refer someone for diagnosis<sup>4</sup>

(<sup>1</sup>Brown et al., 2018; <sup>2</sup>Pei et al., 2016; <sup>3</sup>Lynch et al., 2017; <sup>4</sup>Flannigan et al., 2018)

Once people with FASD are in the justice system, they can be further victimized and return to the justice system. This can lead to ongoing involvement. One of the main reasons for ongoing involvement with the justice system is that people with PAE often do not understand the expectations of the system when they are released, so they breach (do not obey) conditions and are returned to jail (Mela et al., 2019).

Other reasons for long term involvement can include:

- People in the legal system do not understand the disability<sup>1,2,3</sup>
- Lack of support systems in place when released<sup>2</sup>
- Traditional ways in correction not effective<sup>2</sup>
- Limited understanding /comprehension
- Not understanding consequences of their actions
- Limited verbal skills and understanding during hearings, etc.
- Inability to self-advocate

(<sup>1</sup>Mela et al., 2019; <sup>2</sup>Brown et al., 2018; <sup>3</sup> Pei et al., 2016)

This can be reduced by family members or caseworkers or another support person advocating for people with FASD.

People with FASD in the justice system have positive qualities that can help them leave the system (Pei et al., 2018). These factors include:

- hope
- willingness to change
- resilience in looking for a different and positive future

(Pei et al., 2018)

Knowledge of FASD, individualized supports, positive behaviour, and working with the person's willingness to make changes may lead to positive developments. Supports with housing, job skills, and a structured environment could help people make positive moves to the community (Pei et al., 2018). Help in finding social circles that do not have high-risk behaviours is beneficial (Pei et al., 2018). The Alexis program builds capacity, helps understand the offender, creates bridges, and helps people move forward (Flannigan et al., 2017).



The Truth and Reconciliation Calls to Action recognized needs related to FASD in the justice system. Call to Action #34 made several recommendations. A framework for action on this call included these suggestions:

- Mandatory education about systemic racism
- Equal access to paid Gladue reports (pre-sentencing or bail hearing report about what an appropriate sentence might be – taking into account an Indigenous person’s experiences)
- FASD informed training practices for inside and outside the courts
- More therapeutic justice practices
- Enhanced alternative diagnostic practices
- Strengthened community supports
- Putting in place sentencing reform (during the current justice review)
- Removing mandatory court fees
- Strong release plans
- Bail and release conditions that are FASD informed
- Evidence-based evaluations of programs
- Training for communities to develop and do evaluation

(Stewart & Glowatski, 2018)

Saskatoon, Regina, and Moose Jaw have Mental Health courts. The intent is to move people with mental health impacts and FASD away from the courts to community supports such as medical professionals, mental health professionals, or homes. People who take part in these courts must plead guilty. There were positive results found in the two years following participation in mental health courts, such as fewer police contacts and a reduction in being victims of crime and arrests (violent and non-violent) There are still some problems such as not providing a change of address or continuing to socialize with people who are negative influences (Zidenbert et al., 2020).

A review of the mental health court in Saskatoon recommended the following:

- Hire a dedicated coordinator to oversee the program and clients’ case files (e.g., remind clients of appointments, monitor the reward/punishment system, and arrange additional services as needed).
- Adopt a Risk-Needs-Responsivity framework.
- Inclusion of risk-needs assessment at intake, or shortly thereafter.
- Administer a suicide risk screen at intake, or at pre-determined intervals, and make appropriate referrals to Saskatoon Crisis.
- Avoid the use of financial penalties and fines.
- Create a system of penalties and rewards to ensure clients’ compliance with the MHS Court requirements. Re-arrest should only be used as a penalty as a last resort.
- Implement judicial referral hearings as an alternative to administrative charges for participants and address non-compliance with a system of penalties.
- Consider implementing a stay of prosecution by the Crown upon successful completion of the program. Include a graduation ceremony upon successful program completion.

- The inclusion of an Indigenous court worker as one of the professionals involved in the MHS Court, if one is not already included in on the professional Court team.

(Zidenbert et al., 2020)

A new project in Canada is the Integrated Justice Program. The goal is to address over-representation of Indigenous people with FASD in the legal system (FASD Network of Saskatchewan, n.d.). The FASD Network of Saskatchewan is part of this project. Supports are provided to people such as:

- legal advocacy
- peer navigators (mentors)
- courtroom support
- help understanding and following conditions
- probation and parole planning
- release planning
- sentencing support
- access to community support

(FASD Network of Saskatchewan, n.d.)

People with FASD face many risks. Service providers and parents/caregivers can best help when they are educated about how to protect individuals' legal rights and ensure they have appropriate legal representation (Paley & O'Connor, 2009). Experts agree on the need to provide support to people on the spectrum who are dealing with the legal system (Pei et al., 2021).

### Employment

Employment can help develop self-esteem, positive identity, and self-worth. It can also protect against adverse impacts (Green & Cook, 2016). Employment also offers better finances and chances for growth. When individuals with FASD are not employed, they may be at risk of other adverse impacts such as substance use disorders, problems with stable housing, or involvement in the criminal justice system. Happily, people with FASD can be, and are, successful in the workplace.

Employment can also be a challenge for people with FASD. Because of the primary impacts of PAE and life experiences, they may have challenges with:

- paying attention
- being impulsive
- memory
- working with co-workers and employers who do not understand FASD and the needs they may have
- lack of supports
- criminal records
- substance use issues
- not understanding rules and expectations of the workplace
- stigma and negative perceptions about their ability to successfully work
- lack of childcare
- becoming tired because of the extra energy used to concentrate and do the job
- living arrangements
- lack of role models
- involvement with mental health or legal systems

(Green & Cook, 2016)

Success in employment comes from:

- finding the right job fit
- using relational supports
- identifying as having FASD
- responding to challenges
- right number of hours
- low levels of job stresses
- consistent work schedule
- regular routine
- lots of repetition at work

(Kapasi et al., 2019)

Supported employment (SE) models work well for people on the spectrum. SE can help find jobs that are the right fit and provide supports to people in finding jobs, learning the skills of the job, and keeping employment. SE can be successful because it:

- is individualized
- is strength-based
- is person-centred
- provides information about FASD
- works collaboratively to support client
- builds relationships between the individual, the support worker, and employer

(Green & Cook, 2016)

Individuals with FASD can identify areas they may need help with employment. This may include:

- help waking up
- packing a lunch
- eating breakfast
- getting dressed
- help taking medication and tending to hygiene

(Kapasi et al., 2019)

Makela et al. (2018) have developed a guide on how to support adults with FASD in the workplace. It provides information and tips to consider. It can be found at <https://canfasd.ca/wp-content/uploads/publications/Guide-for-Employment-Professionals-Supporting-Employment-in-Adults-with-FASD.pdf>.

Sometimes, once employment is secured, keeping the job is a challenge. Workplace expectations are high. Workers with FASD can experience a range of workplace problems. A few examples include difficulty completing an adequate amount of work through the day (work too slowly), completing the work to the expected standard (hurrying through tasks but with poor quality), managing workplace relationships (conflict with coworkers or supervisors), remembering tasks and workplace rules, and managing time (getting to work on time, taking breaks appropriately).

People who do not have regular income from employment face poverty. Many employers are willing to hire an individual who has faced barriers to employment. Success comes from learning about FASD, creating accommodations in the workplace, adjusting expectations (if needed), assigning suitable tasks, and teaching duties in a way that builds on individual strengths.

Housing and Houselessness/Homelessness

Having stable housing helps people feel safe and secure. They can find it easier to use other supports (Pei et al., 2015). People with FASD are one of the groups at risk of being unhoused (Pei et al., 2018). They may be the most vulnerable in the homeless population (Badry et al., 2015). A study found that 83% of the participants were unable to live independently (Streissguth et al., 1997). They may also have problems finding and keeping a place to live (Badry et al., 2015).

'One size fits all' does not work for people with FASD (Pei et al., 2015). Each person with FASD has different strengths and challenges related to finding and keeping a home. Some adults with FASD will need a high level of daily support to manage tasks like personal hygiene, shopping, paying bills, meal preparation, and house cleaning in addition to the less regular activities like paying rent, repairing items, or problem solving with a landlord or other tenants in an apartment building. Others may only need suggestions or reminders to shovel the walk, keep their home clean, or shop for household items. They may need occasional support to ensure the rent is paid or that maintenance is done as needed.

When helping someone with FASD find housing, a key is placing the person at the centre (person-centred) and work with their particular needs and supports (Pei et al., 2018). This can also include family members and people in their social network (Pei et al., 2015). When the person finds a home, provide ongoing supports as a person's needs, strengths, and supports change (Pei et al., 2018). This should involve a collaborative and person-centred approach, listening to the person with FASD. Experts recommend help for people to access financial supports (Pei et al., 2021).

Many people with FASD can live independently. Others may have difficulties and want and need support. As mentioned in previous descriptions of adverse impacts, the primary impacts of prenatal alcohol exposure can pose challenges. People with FASD may have problems with:

- planning
- paying attention
- memory
- managing time
- taking care of money
- paying rent on time
- understanding the consequences of behaviours
- not turning up for meetings
- behaviour
- substance use issues
- finding and keeping a job

(Badry et al., 2015)

There is no simple answer when it comes to finding housing for people with complex needs (Pei et al., 2018). Many of the challenges of finding and keeping housing for people with FASD is the system around them (Pei et al., 2018). This can include the lack of affordable housing as well as a lack of understanding of people with FASD and their complex needs.

Because of the invisibility of FASD, many people who work with houseless people do not recognize a person has FASD. The workers also may not understand the complexity of FASD. It is very beneficial if the



people supporting them to find housing understand FASD (Pei et al., 2018; Badry et al., 2015). It is also very helpful to remember that each person with FASD is different and will have different strengths and needs. Matching the person's needs to the housing is beneficial (Pei et al., 2018).

Housing for people with complex needs may require:

- adaptable rules
- harm reduction strategies
- guest management
- developing social networks
- providing daily support
- working with landlords (Badry et al., 2015)

Finding the housing that works for a person's needs is important, and people may need help to find the housing that is best for them (Pei et al., 2015). Some people live independently. Other people may experience successful housing if there are supports such as:

- supported living
  - assisted homes
  - individual place with worker checking in
- (Pei et al., 2015)

If someone has been using supportive living, withdrawing services or changing to an independent living situation can cause problems if the person is not ready for this change. There may be assumptions that because the person is successful in one environment, they have developed the ongoing living skills to be successful in another environment (Pei et al., 2018). If the person is not ready, the housing option could fail. Another challenge can happen if workers try to adapt the person to the housing or program and don't adapt the housing to the person (Badry et al., 2015).

When people don't have stable housing, they can experience problems with their health, education, employment, or become involved with the justice system (Pei et al., 2015). They may also avoid other people to stay safe. It is recommended that support workers check with people to make sure they feel safe and secure.

It is very beneficial to have safe and secure housing (Pei et al., 2015). Housing for individuals with FASD should be based on the 7S model: "Safe, stable, secure, supported, supervised, subsidized" (Lutke & Antrobus, 2004, p. 30).

However, whether individuals need a high level of support and guidance or a minimal level, some common factors will help them succeed. Each of these factors is important and must be individualized in order to accommodate the wide range of abilities and needs.

For more information, “Creating Intersections: A Systematic and Person-Centred Harmonizing Framework for Housing Individuals with Fetal Alcohol Spectrum Disorder” provides evidence-based guidance related to housing for persons on the spectrum. It can be found at [https://canfasd.ca/wp-content/uploads/2019/03/FASD-X-Housing-Pei-2018\\_Amended-March-04-2019.pdf](https://canfasd.ca/wp-content/uploads/2019/03/FASD-X-Housing-Pei-2018_Amended-March-04-2019.pdf).

### Relationship and Friendship Issues

This section discusses challenges with relationships and friendships. Before moving into the discussion, it is good to look at the strengths of people on the spectrum. People with FASD have many strengths, but there is not a lot of formal research on their strengths and resiliency. An issue paper on the strengths of people with FASD shared these attributes:

- Friendly, likeable, and affectionate
- Helpful and generous
- Outgoing, verbal, and good storytellers
- Insightful and bright in some areas
- Artistic and musical
- Mechanical and athletic
- Determined, hard-working, willing, and persistent
- Forgiving, non-judgemental, and caring
- Good with children and animals
- Strong hands-on learners
- Excel in non-traditional learning environments
- Work habits
- Good at sports
- Involved in school activities that fit their interests and abilities and create opportunities for friendship
- Participating with youth groups and engaging in elder support
- Reaching out to help others
- Gaining self-insight through FASD diagnosis
- Hope
- Helpful
- Kind-hearted
- Successful with hands-on, visual, and physical activities

(Flannigan, Harding, et al., 2018)

Due to PAE and its impacts on the brain, people with FASD have qualities and realities that can make them susceptible to pressures and influences (CanFASD, 2021). They may not function at the level that is expected for their chronological age. They may also have uneven development with strengths in some areas and vulnerabilities in others (CanFASD, 2021). As individuals age, society has expectations for them that they may not always be able to meet (CanFASD, 2021). Their challenges in meeting social expectations can lead to negative outcomes such as being victimized and manipulated. A study of people with FASD showed people who were vulnerable to manipulation were significantly more likely to have mental health problems (Clark et al., 2004). Individuals with FASD may not be accepted by their peers (CanFASD, 2021). More research is needed to explore the impact of social pressures on people with FASD (CanFASD, 2021).

Due to the primary impacts of PAE, children with FASD have impacts on their social skills and the development of relationships. The social skills of children with FASD are lower than their peers and do not improve as they get older (Streissguth et al., 1991; Kully-Martens et al., 2012). Impacts have included:

- being inappropriately friendly
- having problems with their peers
- experiencing teasing or bullying
- having problems with social judgement
- experiencing problems reading social cues
- behaviour regulation

(Kully-Martens et al., 2012)

The neurological injury from prenatal alcohol exposure changes how individuals process, express, and act on emotions. The primary impacts (e.g., neurobiology, executive function, sensory processing, and communication skills) related to PAE can cause interpersonal and relationship problems. For example, some individuals may seem cold, unemotional, or “flat” in their demeanour. This makes it hard for others to feel a sense of connection with them. Others may lack the level of interpersonal sophistication required for different kinds of relationships. They may have a poor understanding of personal boundaries and get in other people’s space, phone too often, or drop by at inconvenient times. Social awkwardness in using conversational skills, responding to humour, or showing empathy or sensitivity may impede their ability to develop deep connections, and as a result, they only develop superficial relationships.

People with FASD have difficulty making and keeping friends (Kully-Martens et al., 2012; Roozen et al., 2020). This starts young and can continue throughout life (Kully-Martens et al., 2012). Age-related differences in social skills become worse as they grow older (Kully-Martens et al., 2012). Self-esteem can be impacted, and mental health issues may occur.

In addition to difficulties with the subtleties of relationships, the chronic poor fit experienced by individuals with FASD can prompt individuals to seek out a sense of belonging with others even if the relationship is inappropriate, unsafe, or violent. For example, many parents are deeply concerned about their teens or adults seeking friendships with those much younger. Because of their developmental dysmaturity, they have social behaviours more similar to younger people and feel more at ease with them (Malbin, 2006). Such friendships can be unsafe and should be carefully monitored.

Violent relationships are also a concern. Families and service providers frequently report that teens or adults experience a series of difficult and broken relationships or stay in long-term problematic, violent relationships. Women may be victimized because they want to belong in a group and be accepted, loved, and cared for (Rutman & Van Bibber, 2010). The extreme vulnerability to victimization, abuse, and exploitation combined with a desire to please others and be accepted is a dangerous combination. Youth and adults with FASD may also be at risk of abusing or exploiting others. They are vulnerable to explosive reactions and impulsive behaviours or acting in a multitude of other ways that destroy relationships and make it hard to connect with or trust them.

There are interventions that can help with social skills. Children Friendship Training (CFT) has been used with children (Kully-Martens et al., 2012). Theatre-based interventions have been used with young people and has helped youth with FASD develop an awareness of their emotions and develop social skills (Keightley et al., 2018). Another activity that provides social benefits is physical activity (Pei et al.,

2015). People with FASD can be successful when involved in physical activity and experience ‘teachable moments’ (Pei et al., 2015).

People with FASD have identified their challenges with friends and employment makes them feel different from others. It also impacts their day-to-day lives (Domeij et al., 2018). Individuals with FASD may have troubled relationships with immediate or extended family members. Although some youth and adults with FASD may not seem to need help in making or keeping friends or creating a circle of support, other individuals may need a great deal of support in creating a circle of safe and healthy friends.

### Sexuality

Sexual feelings are normal and healthy. Sexuality is complicated. Children, youth, and adults with FASD share the same physical changes and desires as everyone else.

For people with neurotypical development and those with atypical development, teaching about sex and relationship safety is a protective factor (Pei et al., 2015). Teaching and talking about sexuality are best when they happen early and are an ongoing conversation. This conversation should also include contraception, Sexually Transmitted Infections (STIs), and safe sex (Paley & O’Connor, 2009; Pei et al., 2015). Unfortunately, some families and caregivers have not discussed sexuality because of a belief that people with disabilities are asexual (Anderson et al., 2018). There may also be a need to reteach. Each individual is different, and their needs will be different.

People with FASD may not be as mature socially and emotionally as they are chronologically in age. For this reason, they may need extra support to learn about healthy and safe sexuality. They may not have the sexual knowledge of others their age and need more teaching, re-teaching, or teaching in a different way. Many people do not find it easy to discuss sexuality. People, such as a worker they trust, can help them understand where they are vulnerable, find support to help, and create safety plans (Pei et al., 2015).

The Public Health Agency of Canada suggests that individuals with developmental disabilities should receive sexual health education tailored to the person’s needs and disability. It recommends:

- understanding what is relevant to their specific health needs and concerns
- the confidence, motivation, and personal insight needed to act on that knowledge
- the skills necessary to improve sexual health and avoid negative sexual health outcomes
- a safe, secure, and inclusive environment promotes the best possible sexual health

(Public Health Agency of Canada, 2008)

All people also need access to reliable and safe birth control methods to minimize the likelihood of unintended pregnancies. People with FASD may need help with this. Because of memory impacts, Depo-Provera could be a good option (Pei et al., 2015).



Because of the impact of PAE such as memory deficits, suggestibility, social skills, impulsivity, and confabulation, individuals with FASD may be vulnerable to victimization or inappropriate sexual behaviour (ISB). They have trouble reading social cues, facial expressions, or knowing who might be appropriate for a date or partner (Novick-Brown, 2007). They may interpret a friendly smile as a sexual advance and then respond with inappropriate or offensive behaviour to the other person. Abstract concepts can also cause problems. Abstract concepts include:

- risk
- consent
- appropriateness
- boundaries

(Anderson et al., 2018; Mela et al., 2019)

It has been suggested that individuals on the spectrum who experience inappropriate sexual behaviour be assessed about their social-sexual knowledge and attitudes. A tool that could be used is the Social Sexual Knowledge and Attitudes Assessment Tool-Revised (SSKAAT-R) (Lunsky et al., 2007).

Another suggestion to be considered for individuals with FASD is the theory of counterfeit deviance. Counterfeit deviance is described as “people with intellectual disabilities, because of their unique histories and unique living situations may engage in deviant behaviour for reasons other than deviance” (Griffiths et al., 2013, p. 13). People with FASD can be involved with inappropriate sexual behaviour either as a victim or offender (Anderson et al., 2018; Mela et al., 2019). Due to brain differences, some people with FASD may have impaired sexual socialization (Novick-Brown, 2007). In order for inappropriate sexual behaviour to be addressed, the individual must feel that it is safe to share such personal details and feel that they will not be shamed or embarrassed.

People may victimize individuals on the spectrum because of the primary impacts of FASD (Bown et al., 2018; Streissguth et al., 1996). For example, they may be convinced to send naked pictures of themselves over the internet, expose themselves, or masturbate in public. They may use these same inappropriate behaviours when they are older because they experienced them. They may struggle with impulsivity, aggression, anger, or trauma they have experienced (Brown et al., 2018). They may not even realize this type of behaviour is inappropriate. They can then be in trouble with the law.

Some of the struggles reported by families and discussed in research around the issue of sexuality include:

- sexual advances directed toward inappropriate persons
- unwanted or illegal sexual touching
- exploitive sexual behaviours, sexual coercion, or violence
- stalking behaviours
- unplanned pregnancy
- exposing self to others
- sexual compulsions
- voyeurism
- sexual activity or masturbation in public
- obscene phone calls
- promiscuity
- involvement in sex trade

(Novick-Brown, 2007)

Women may be victimized because they want to belong in a group, and feel acceptance, love, and care (Rutman & Van Bibber, 2010). They may use poor judgement and seek out inappropriate sexual behaviours because of a lack of awareness of what is appropriate or lack appropriate social skills. In some cases, sexual behaviour may be impulsive.

Research indicates that about half of adolescents and adults with FASD engage in inappropriate sexual behaviour (ISB). This was found to cut across the life span, increasing with increases in age (Streissguth et al., 2004). Another finding from the same study is the direct association between being a victim of physical/sexual abuse and violence and inappropriate sexual behaviour. Moreover, the described behaviour leaves individuals at risk for sexually transmitted diseases and unplanned pregnancies (Paley & O'Connor, 2009).

There is no research about FASD informed treatment for sexual offences or relapse prevention strategies (Anderson et al., 2018). It is suggested that screening for FASD be done (Anderson et al., 2018). An understanding of FASD and adapted interventions and treatments may better meet the needs of the person (Anderson et al., 2018; Mela et al., 2019).

Professionals should create a multi-disciplinary team to intervene with these behaviours. This may include legal professionals, service providers, social workers, and family members (Brown et al., 2018). It is also helpful to examine the risk factors related to the individual and their environment. This includes:

- the individual's ability to act independently and make decisions
- determination of the level of sexual risk
- attitudes, perceptions, and stimuli

(Anderson et al., 2018)

There is a need for more research in this area.

### Parenting with FASD

Many people in Canada are parents. There are many reasons people become parents. For some, it is a choice, and for others, it may be unintended. Up to 50 per cent of pregnancies are unintended (Finer & Zolna, 2016; Sedgh, Singh, & Hussain, 2014). Whether individuals become parents by choice or by circumstance, parenting is a challenge.



The prevalence of FASD in Canada estimated to be approximately four percent of the population (CanFASD, 2021). This means there are parents with FASD who may or may not be diagnosed. People impacted by prenatal alcohol exposure may need a great deal of support to ensure they have a healthy pregnancy that is free of harmful substances like alcohol and drugs (Gelb & Rutman, 2011). Programs that utilize harm reduction and provide wraparound support for pregnant people (including those with FASD), can support them to have healthy, substance-free pregnancies. Some of these programs also

provide follow-up support after the birth of the child. Examples include Breaking the Cycle (Toronto), the Mothering Project (Winnipeg), Sheway (Vancouver), and Sanctum 1.5 (Saskatoon). More information about these programs is found in Module 6: Prevention of FASD.

Parenting requires many skills such as problem-solving, decision-making, managing emotions, regulating stress, detecting subtleties, managing money, balancing priorities, expressing empathy, and more. Parenting is not easy for anyone and can be more challenging for people with neurological differences. Some individuals may be successful parents, some may need ongoing assistance, and others may not be able to parent. Parents and caregivers worry about their children's ability to function as parents, and many caregivers are raising their grandchildren (Harding et al., 2020). The parents of adults with FASD commonly find they are supporting their adult child and involved in caring for their grandchildren. The degree of care grandparents provide varies; support needs may range from minimal support to a high level of support where grandparents assume the majority of responsibilities (emotional, time, financial, and physical) for raising their grandchild or grandchildren (Lutke & Antrobus, 2004).

Primary effects of PAE that can impact parenting include problems with memory and organization; perseveration; planning; generalizing from one situation to another; using consequences effectively; understanding the concept of time; registering and integrating sensory cues such as hunger, temperature, and pain; and temper/patience and impulsivity. (Rutman & Van Bibber, 2010).

People with FASD come from a variety of home backgrounds. Some have come from caring homes, others from multiple homes in the social services system, and others may come from dysfunctional homes. Their experiences growing up may also impact their ability to parent. Someone who has experienced poverty, substance misuse in the home, abuse, lack of positive role models and social supports, and homelessness may struggle with parenting skills (Rutman & Van Bibber, 2010).

People with FASD have hopes and dreams for themselves and their children. In one study, parents with FASD (male and female) identified hopes that their children would be good people and have better lives than they did. They also wanted to break the cycle, although the cycle had different definitions, such as:

- substance use
- foster care
- no involvement with children
- abuse or neglect

(Rutman & Van Bibber, 2010)

In this same study, parents with FASD identified these positives:

- Raising children and/or getting them back from foster care
- Children showed affection and attachment
- Using positive parenting strategies
- Finishing school
- Having employment
- Dealing with anger issues
- Stopping or reducing substance use
- Using daily living skills to successfully parent
- Using memory aids
- Using self talk for transitions
- Consistency in daily activities

(Rutman & Van Bibber, 2010)

There is often an assumption that people with FASD are not able to raise their children (Choate, 2013). However, people with FASD can successfully parent. Parenting is also an opportunity to provide supports that can reduce negative impacts and help to develop coping skills to deal with the primary impacts of PAE (Rutman & Van Bibber, 2010). Parents may be afraid to ask for help because it may lead to the involvement of social services and the loss of their children (Rutman & Van Bibber, 2010). An irony that parents with FASD can experience is the negative judgement of their parenting abilities because of PAE but also that service providers would minimize the impact of PAE or overrate their abilities (Rutman & Van Bibber, 2010).

A strength-based approach with a circle of support can help people with FASD be successful parents (Choate, 2013). As mentioned previously, a person-centred approach with an understanding of FASD works best. It can adapt to the needs, challenges, strengths, and experiences (Harding et al., 2020).

There has not been a lot of research on programs to support parents with FASD. Two pilot studies showed that parents with FASD can do well with paraprofessional case managers and mentors. The programs were based on the Parent-Child Assistance Program (P-CAP). This 3-year program provides help with substance use, and a paraprofessional advocate case manager for three years. There were improved outcomes for the mother and child (Petrenko, 2015). The program helped reduce substance use, increased the use of contraception, helped people obtain housing, deal with hygiene, safety, food, and access healthcare and community services (Harding et al., 2020). P-CAP has also helped people get a diagnosis of FASD.

For anyone raising children, the most important part is the safety and health of children. All children need to be safe and free from harm. It does not matter if the parent is neurotypical or not. If children are unsafe, steps need to be followed to ensure safety. Parents with FASD have experienced the pain and trauma of having children apprehended, losing custody of their children, or making the difficult decision not to be actively involved as a parent. One early study found that for women affected by FASD who had given birth, more than half of them no longer had their child/children in their care (Streissguth, 1996). This experience is traumatic for all involved but is a clear risk for adults with a disability who are parenting. Susan Opie (2009) echoed this concern and stated: “Preventing pregnancies in someone who cannot parent or who could not manage an additional child at this time is critical. Having to give up a child to a family member or to child welfare is a devastating event, with potential long-term negative outcomes for the adult with FASD, (e.g., grief and loss, increased substance abuse)” (p 11).

Service delivery that would support parents well include:

- support related to sexual health, contraception, and understanding the risks of drinking when pregnant
- basic needs
- supportive mentorship
- strength-based support

- FASD-informed  
(Harding et al., 2020)

### **Transitions: Providing Services to Individuals with FASD**

Individuals with FASD can face challenges as they age out of the child/youth system to adult system. They lose the supports of the youth system but still have challenges. They now have to cope with the expectations and responsibilities of adulthood (Pei et al., 2015). Research suggests they benefit from:

- inclusion of a functional context
- individualized support
- education for service providers
- structure and routine
- utilizing a strength-based approach
- environmental adaptations

(Quan et al., 2019)

Guiding practices that have evidence or expert consensus for people with FASD who receive individualized services include:

- early interventions
- positive strength-based supports
- age-appropriate services
- consistency in staff supports
- interdependence focus, not independence
- sensory processing disorder awareness and supports

(Pei et al., 2021, p. 5)

Pei et al. (2018) provides these thoughts for service providers related to FASD.

- Are staff members confident in ability to provide services or to refer people to other services?
- Are services consistent in agencies in relationships and understanding of FASD and its complex needs to provide stability even with staff turnover?
- Is there collaboration between organizations (e.g., case management, referrals, planning)?
- Are organizations responsive and adaptable to individual needs?
- Are agencies proactive – do they anticipate changes/transitions and plan to move through the change in proactive ways?

For organizations:

- Is there an FASD competent workforce in all systems of care?
- Is training framed from a disability context?
- Are support workers current on FASD-related information?
- Are there support and education for vicarious trauma?
- When hiring, have there been examination of employee interpersonal and work skills?
- Is there familiarity with complex case management?

To best support people with FASD to be the best they can be, provide services that:

- are appropriate for the chronological and developmental age
- promote interdependence, not independence
- provide consistency and structure

- have awareness and support for sensory processing disorder (Pei et al., 2018)

### **Conclusion**

- Individuals affected by prenatal alcohol exposure commonly develop adverse impacts.
- These adverse impacts and characteristics develop due to complex interactions of biological impacts, life experiences, lack of support, and lack of FASD-informed services.
- Adverse impacts can include addictions, mental health issues, problems with the law, houselessness/ homelessness, problems with education, lack of employment, problems with relationships, issues with sexuality, and struggles with parenting.
- Adverse impacts tend to stack up. One adverse impact can be a risk factor for the development of others.
- Effective FASD-informed, long-term, individualized support and accommodation in all aspects of life, and from various service providers, can improve outcomes and reduce the risks of developing adverse impacts.
- Effective intervention for adverse impacts requires an understanding of FASD as a whole-body disorder with physical and brain-based effects with behavioural signs and symptoms.

### **Suggestions for Further Learning**

Canada FASD Research Network (CanFASD)

<https://canfasd.ca/>

FASD Network of Saskatchewan

<https://www.saskfasdnetwork.ca/>

Canadian Centre on Substance Use and Addiction (CCSA)

<https://www.ccsa.ca/>

KNOWFASD – is a resource and information website created by the “[Intervention on FASD](#)” Network Action Team (iNAT) of the [Canada FASD Research Network](#). Information accurate as of 2018

<http://knowfasd.ca/>

The FASD Centre at the Regina Community Clinic

1106 Winnipeg St.

Regina, SK S4R 1J6

Phone 306.543.7880 ext. 268

<https://www.reginacommunityclinic.ca/fasd/diagnosis-assessments/>



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