Module 8

Young Children with FASD: Primary Disabilities, Adverse Impacts, and Strategies

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Introduction

In Canada, FASD is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol (Canada FASD Research Network, 2019). FASD is a lifelong disability and individuals with FASD usually experience some level of challenges in their everyday lives. Individuals living with FASD may require support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential (CanFASD, 2019).

FASD is complex and not quickly explained. An understanding of the primary impacts of prenatal alcohol exposure (PAE) leads to better supports for children. This can reduce frustrations for the child, parents, and other people in the child's life. "Our approaches must always be strength based, empowered, and goal oriented" (Pei et al, 2019, p. 4). With the right supports, attitude, and strategies, children with FASD can be successful. This reduces the development of adverse impacts and challenges (formerly called secondary disabilities).

This module provides information on primary impacts of prenatal alcohol exposure and protective factors to help reduce adverse impacts and support success. Early intervention and supports benefit children with FASD. There is not a large amount of peer-reviewed research on interventions for children who were prenatally exposed to alcohol. Many programs and recommendations for supports may have limited research, other than subjective assessment, documenting their impact (CanFASD Northwest, 2011). As a result, some of the practices noted in this module will be taken from resources created for families and not peer-reviewed journals.

This module begins by describing the key challenges (primary disabilities) that can impact everyday life for children with FASD, ages 0 to 6. This module then introduces promising strategies that can be put in place to reduce the adverse impacts that can be experienced as a result of these challenges. Specific caregiver strategies that can be used to address key challenges experienced by children with FASD are also discussed.

Strengths

Examining the primary impacts of prenatal alcohol exposure can cause one to forget that each child (and adult) with FASD has strengths. There is little formal research about the strengths of people with FASD (Flannigan et al., 2018; Flannigan et al., 2020) and more research is needed. Recognizing strengths can help to reduce stigma related to FASD (Flannigan et al., 2020). Children with FASD can be successful and "there is a need for opportunities that support them to do so" (Flannigan et al., 2020 p. 7).

Non-academic literature lists positive traits such as these:

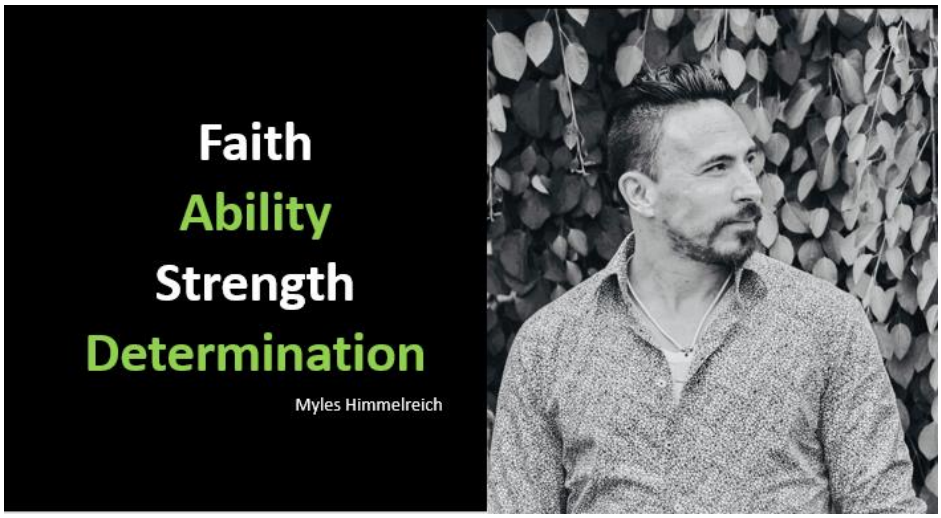
- Friendly, engaging, social, and outgoing
- Affectionate
- Likeable
- Willing, helpful, and generous
- Verbal and good storytellers
- Insightful and bright in some areas
- Creative, artistic, and musical
- Mechanical
- Athletic
- Determined, hard-working, and persistent

- Forgiving and non-judgemental
- Caring and compassionate
- Good with children and animals
- Hands-on learners
- Excel in non-traditional learning environments
- Resilient
- Alert
- Funny
- Innocent
- Straightforward
- Curious
- Bring an intriguing perspective to the experience of life

(FASD Network of Southern California, 2018; Flannigan et al., 2018; Petrenko et al., 2019; Olson & Montague, 2011; SNAP, 1999)

As one goes through this module, it is hoped strengths will be remembered. Children with FASD can experience success when teachers and the people in their lives are aware of their strengths and FASD informed (Flannigan et al., 2018). Understanding FASD can also lead to some creative solutions (Badry & Hickey, 2018). It is important for children and adults to know they have strengths. It also is important to remember that each person who has been prenatally exposed to alcohol is unique.

Myles Himmelreich, a motivational speaker, advocate, author, consultant with FASD, speaks of FASD in a different way. He talks of "faith, ability, strength, determination" (Videos — Myles Himmelreich).



Understanding FASD as a Disability

The cognitive, behavioural, physical, and sensory primary impacts associated with PAE are very unpredictable "in both the manner and the extent to which the effects are exhibited" (Paley & O'Connor, 2009, p. 259). No two children experience FASD in the same way. Children who were prenatally exposed to alcohol may show significant primary effects and impairments in some areas of functioning and show significant strengths in other areas. This adds to the difference (Paley & O'Connor, 2009).

FASD is Lifelong

As mentioned earlier, the primary impacts of prenatal alcohol exposure are lifelong. Even though the characteristics of the disabilities change as a child grows and progresses through the life stages, these primary impacts "do not disappear or even diminish with age" (Lutke & Antrobus, 2004, p. 12.). Early and appropriate supports can make a positive impact and improve outcomes for children and adults with FASD (CanFASD, n.d.).

FASD is Often Invisible

FASD is not physically visible for most children. A small number of children diagnosed with FASD (approximately one in 10) will have certain distinctive facial features and/or growth deficiency (CanFASD, 2019).

For most children with FASD, it is difficult to spot the range of permanent impacts caused by prenatal alcohol exposure. Since the brain develops throughout the entire gestational period, it is vulnerable to the harmful effect of alcohol exposure throughout the pregnancy. The physical changes to the brain make FASD a physical disability, but one that is most often unseen. What is visible is the behaviour and functioning of the child, which can be caused by alcohol's impact on the brain (Cook et al., 2015). Since the physical injury is not seen, it is difficult for many people to understand and accept that brain processes and functions may have been affected. This is one reason why FASD is often referred to as an invisible disability.

Primary disabilities are present from birth but may go undetected.

Understanding FASD is also complicated by issues such as:

- misdiagnosis
- co-occurring diagnoses (often several impairments or diagnoses are identified)
- the overshadowing of the primary disability by later adverse impacts like addictions
- the silence around FASD
- difficulties associated with accessing diagnosis

(Gelb & Rutman, 2011)

Primary Disabilities of FASD

The range of primary impacts from PAE is broad. The common primary disabilities associated with FASD include:

- Cognitive (e.g., thinking, remembering, speaking, reasoning, perceiving, solving problems)
- Behavioural (e.g., actions, reactions, voluntary and involuntary activities, which are controlled by brain function)
- Physical (e.g., body organs, skeletal and muscular systems, motor development)
- Sensory (e.g., taste, smell, touch, hearing, seeing, pain tolerance)

(Saskatchewan Prevention Institute, n.d.)

FASD is a Neurobehavioural Disability

As previously mentioned, the primary disabilities associated with FASD are mostly not seen and always complex. Although one cannot see the injury to the central nervous system, one can see the behavioural signs and symptoms of this injury. The wide assortment of behavioural signs and symptoms, referred to as neurobehavioural characteristics, are characteristics by which FASD is defined and described.

> Neurobehavioural:
>
> Of or relating to the relationship between the action of the nervous system and behaviour
>
> Merriam Webster (n.d.)

There are ten different domains of brain functioning that can be affected by prenatal alcohol exposure. A diagnosis of FASD is made when there is severe impairment in three or more of the domains (Cook et al., 2015). The domains are:

- neuroanatomy/neurophysiology (brain structure and function)
- adaptive behaviour, social skills, and communication
- attention
- cognition
- executive functioning, including impulse control and hyperactivity
- language
- memory
- affect regulation
- academic achievement
- motor skills

Table 8.1 provides more explanation of the domains.

Table 8.1 Ten Brain Domains Associated with FASD Diagnosis

Domain	Example
1. **Motor skills** How the muscles move and act	Fine motor skills (small muscles), gross motor skills (large muscles), muscle tone, reflexes, balance, coordination
2. **Neuroanatomy/ Neurophysiology** How the brain and nervous system are built and work	Brain structure, head size, seizure activity
3. **Cognition** How one learns, understands, and gains knowledge	Thinking, perception, and reasoning

Domain	Example
4. Language How one uses and understands language	Ability to hear and interpret language and communicate to others (verbal or nonverbal)
5. Academic achievement How one progresses in school subjects	Includes measures of math, reading, and writing
6. Memory How one stores information and remembers it when needed	Remembering what is heard (auditory) and what is seen (visual) Remembering information over time
7. Attention How one focuses and stays on task, including with those tasks that are less enjoyable or more challenging	Ability to ignore or tune out distractions
8. Executive function ("Boss of the Brain") How mental skills are used to get things done	Impulse control, planning, problem solving, organizing, controlling one's thoughts, following instructions, understanding abstract concepts (e.g., time, value of money)
9. Affect regulation How one controls emotions, reacts to stress, and reacts to different situations	Includes current or possible mental health diagnoses (e.g., depression or anxiety)
10. Adaptive behaviour, social skills, social communication How one manages everyday life and social situations	Ability to take care of oneself (everyday life skills), and respond age-appropriately to others
***Sensory** How one responds to different sensations like touch, movement, sound, smell, sight, and taste When someone is being assessed for a diagnosis of FASD, the person's response to different sensations such as touch, movement, sound, smell, sight, and taste is not included in the assessment; however, the sensory response can impact all brain domains.	

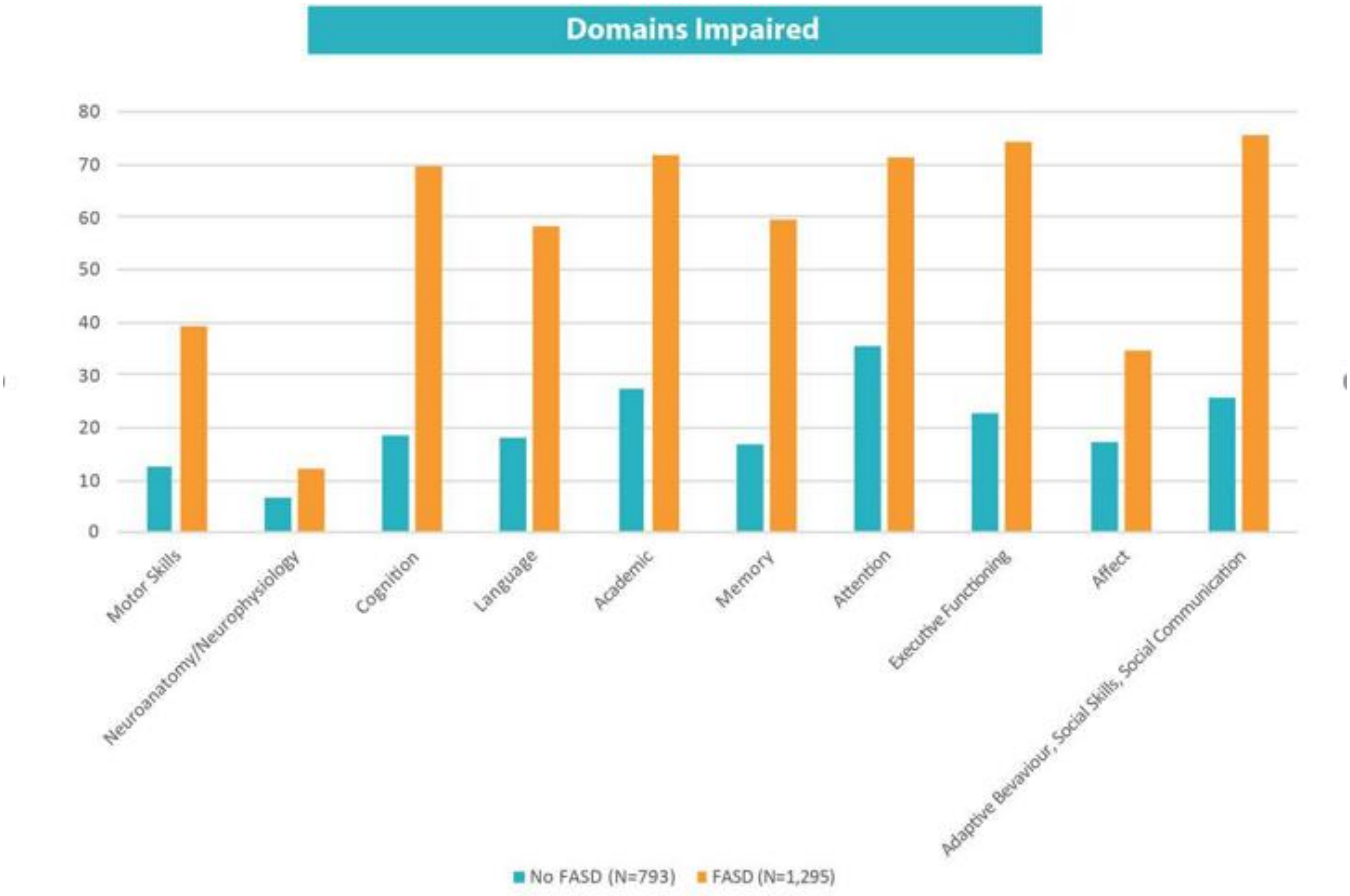
Source: Adapted from the Provincial Training Handbook on Fetal Alcohol Spectrum Disorder (n.d.) from Healthy Child Manitoba.

The categories of impact help with understanding of the neurobehavioural characteristics seen by service providers and families. Grouping brain domains and associated central nervous system impairments offers several benefits to advancing knowledge in the study of FASD. For example, "the brain domains can be tested, compared to standardized norms, and the data used as the basis to

develop supports and interventions. The creation of understandable, usable domain categories empowers caregivers, teachers, judicial, and social service workers, as well as others, to view FASD as worthy of their attention and within their knowledge base to implement change for individuals affected" (Lang, 2006, p. 5).

The Canada FASD Research Network hosts the National FASD Database. The database contains information on referrals for assessment, functional diagnoses, difficulties, challenges, needs, and treatment plans from participating Canadian clinics (Cook et al., n.d.). It is the only database of its kind in the world. The information from the database helps with understanding FASD and making recommendations to policy makers (Cook et al., n.d.). The 2019 Annual Report from the database provided information from 2,211 records from Canadian clinics (CanFASD, 2019). Figure 8.1 provides a snapshot of the brain domains (from the files in the database) impacted by prenatal alcohol exposure.

Figure 8.1 Brain Domains Impaired



Source: The National FASD Database 2019 Annual Report (CanFASD, 2020, p. 10)

Physical Disabilities/Health Challenges

Physical development includes growth of the body size (weight and height), growth of the body organs, growth and development of body systems like the skeletal and muscular systems, growth and development of the sensory system, and development of motor functioning. The process of aging is also part of physical development. The body systems and organs change as one ages.

Prenatal alcohol exposure can impact how the body grows and develops and can cause a range of physical signs and symptoms (Chudley et al., 2005). Recent research shows that children and adults with FASD are more likely to have many health conditions than members of the general population (Popova, Lange, Shield et al., 2016). More than 400 health impacts have been found to co-occur with FASD (Popova, Lange, Shield et al., 2016). They include a wide range of birth defects, and mental and behavioural disorders (Popova, Lange, Shield et al., 2016).

The peripheral nervous system consists of all neurons that exist outside the brain and spinal cord. This includes long nerve fibers as well as ganglia made of neural cell bodies. The peripheral nervous system connects the central nervous system (CNS) to various parts of the body.

https://biologydictionary.net/peripheral-nervous-system/

The five most common conditions in people with FASD include:

- defects of the peripheral nervous system
- ongoing infections of the middle ear (chronic serious otitis media)
- ability to understand words when someone else is saying them (receptive language disorder)
- ability to use words (expressive language disorder)
- behavioural and emotional problems (conduct disorder)

(Popova, Lange, Shield et al., 2016)

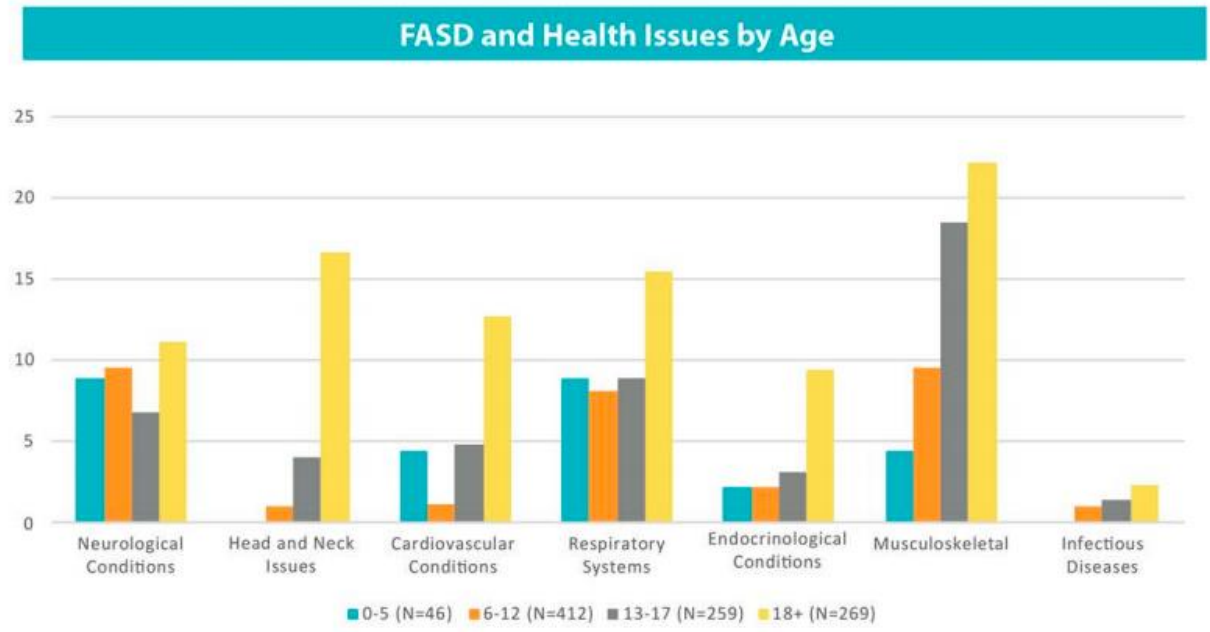
Numerous other health impacts co-occur with FASD. Other frequent health issues associated with FASD that require ongoing monitoring by healthcare providers include:

- reduced growth[4]
- vision problems[1]
- hearing problems[1]
- chronic serious otitis media[5]
- heart defects[1,2]
- seizures[1]
- weakened immune system[1]
- sleep issues (e.g., nightmares, wakefulness, unable to fall asleep and/or stay asleep)[1,3,4]
- feeding difficulties[1]
- elimination concerns[1]
- dental health[1,2]
- Poorer functioning or poorly developed body systems including skeletal, muscular, renal, and circulatory[5]

([1]Hanlon-Dearman et al., 2015; [2]Paley & O'Connor, 2009; [3]Hanlon-Dearman et al., 2018; [4]Cook et al., 2015; [5]Popova, Lange, Shield et al., 2016)

Figure 8.2 shows health issues experienced by people with FASD broken down by age, from the Canada FASD national database.

Figure 8.2 FASD and Health Issues by Age



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

Individuals living with FASD, Myles Himmelreich, C.J. Lutke, and Emily Travis Hargrove, partnered with professionals in the field of FASD to create an anonymous, community-based health survey for people with a confirmed diagnosis of FASD. The responses showed high numbers of health issues and at much higher rates than the general population (Begun & Murray, 2020). The survey also indicated that health issues occurred earlier in people with FASD (Begun & Murray, 2020). The responses show that health issues may be another impact of PAE and health practitioners should pay attention to the health complaints made by children and adults with FASD (Begun & Murray, 2020). More research should be done in the area of health issues.

Physical impacts and symptoms that reflect neurological impairment may include:

- delayed motor development – slow to meet developmental milestones[1]
- problems with fine and gross motor skills – especially noticeable as children reach school age and begin classroom activities with their peers[2]
- problems with motor control and grip (e.g., unintentionally breaks things)[3,4]
- poor hand-eye coordination[2]
- poor balance or coordination – appears clumsy[3,2]
- hearing impairments and auditory processing problems[5]
- sensory sensitivities[3]

- attachment challenges[3]
- difficulties with sensing self in space and movement[3]
- balance problems[3]

([1]Subramoney et al., 2018; [2]Riley & McGee, 2005; [3]Cook et al., 2016; [4]Jirikowic, 2007; [5]McLaughlin et al., 2019)

Strategies for Supporting Health Issues

The healthcare provider plays an important role in the long-term physical and mental health of children with PAE. Hanlon-Dearman et al., (2015) developed an anticipatory guidance document for doctors to watch the health of children and adults with FASD. The document includes tables identifying potential challenges and what to watch for in the care of children with PAE, and items to discuss with caregivers. Table 8.2 includes information for the care of children under the age of six.

> Anticipatory Guidance
>
> Information about normal expectations of an age group (or of a disease) to provide support for coping with problems before they arise. It is a component of many heath care encounters (e.g., well child checkups in infancy).
>
> (Medical Dictionary, 2009)

Table 8.2. Anticipatory Guidance for Children Under Six with FASD

	Anticipatory Guidance
Birth to 1 month	• **Self-regulation:** Infants with prenatal alcohol exposure and/or other prenatal substance exposure may have difficulty regulating their body temperature, movements, and reactions to their environment. They may be jittery, irritable, and show tone abnormalities. Infants may respond to swaddling, calm quiet environments, and patient well-regulated caregiving. Parents may benefit from counselling and respite care. • **Sleep:** Further evidence of abnormal self-regulation may be poorly regulated sleep, reduced sleep, or disrupted sleep patterns. Parents may benefit from sleep consultation and respite. • **Feeding:** Infants may have poorly coordinated suck and swallow, regurgitate more frequently. They benefit from patient responsive feeding practices. Parents may need consultation from feeding specialists and occupational therapists.
1 month to 1 year: Infancy	• Behavioural disturbance including difficulties with self-regulation, disorganization, emerging hyperactivity, emotional dysregulation. • Discuss attachment behaviours and healthy parent/child interactions; refer for supports in high-risk groups and as needed. • Feeding disturbances including food selectivity and atypical feeding behaviours. • Screen for sleep disturbances. • Daycare: issues related to sensitivity to environmental change, behavioural management. • Discuss early intervention supports in the community including developmental supports, mental health services, and therapy supports including physiotherapy, occupational therapy, and speech and language therapy. • Caregiver support and respite.

	Anticipatory Guidance
1 to 5 years: Early Childhood	• Discuss school readiness and support early intervention programs aimed at academic and social emotional health. • Discuss neurobehavioural differences in learning and social behaviour and need for continued and increased supports with age as adaptive gaps widen. • Education re: behaviour in context of prenatal alcohol exposure "reframing behaviour". • Education and support re: sleep disorder – refer for consultation as needed. • Discuss need for caregiver support and respite. • Advocate for educational and community-based supports for child

Source: Adapted from Anticipatory guidance for children and adolescents with fetal alcohol spectrum disorder (FASD): Practice points for primary health care providers (Hanlon-Dearman et al., 2015)

Methods of supporting health in children with FASD include:

- medications
- surgeries
- nutritional supplements
- health education
- exercise

(Hanlon-Dearman et al., 2015; Murawski, Moore et al., 2015 as cited in Pei et al., 2018)

Omega-3

Omega-3 fatty acids have anti-inflammatory and antioxidant properties. These properties help decrease the death of cells (Gomez-Pinilla, 2008, as cited in Patten, et al. 2016). This helps continue typical brain function (Gomez-Pinilla, 2008; Simopoulos, 2009, as cited in Patten et al., 2016) and supports learning and memory. A study on rats showed that omega-3 helped with making memories and new neural networks on males, but not female rats with PAE. Studies using rats have shown some benefits. More research is needed.

Choline

Choline helps the brain and nervous system with memory, mood, controlling muscles, and other tasks (National Institutes of Health [NIH], 2019). It also helps form membranes on the cells in the body. It is found in meat, dairy products, potatoes, whole grains and some beans, nuts, and eggs (NIH, 2019).

Some small-scale studies have shown potential benefits of using choline supplements as an intervention in the early years (Wozniak et al., 2020). A recent small follow-up study was done of children, who ranged between the ages of two and five, and had received choline. Four years after receiving choline there were still positive outcomes in some areas of cognitive effects. Parents reported improvements in attention and behavioural regulation (Wozniak et al., 2020). Interventions such as choline may someday be used with other interventions and accommodations to help children with FASD with their needs (Wozniak et al., 2020). More research needs to be done.

Exercise

Exercise enhances brain plasticity (Hamilton et al., 2015). Some animal studies have been done to see if exercise can help with impact of prenatal alcohol exposure. Exercise may not help all impacts related to PAE, but exercise may be a benefit with some learning and memory impacts (Patten et al., 2015). A few studies have shown there may be gender-related differences in the effects of alcohol and benefits of exercise (Patten et al., 2015).

Medications

There are no medications specifically developed for FASD (CDC, 2020). Some types of medications that may used with FASD are:

- Stimulants (to treat symptoms such as hyperactivity, problems paying attention, and poor impulse control, as well as other behaviour issues)
- Antidepressants (to treat symptoms such as sad mood, loss of interest, sleep problems, school disruption, negativity, irritability, aggression, and anti-social behaviours)
- Neuroleptics (to treat symptoms such as aggression, anxiety, and certain other behaviour problems)
- Anti-anxiety drugs (to treat symptoms of anxiety)

(CDC, 2020)

Psychotropic Medications

Psychotropic drugs affect behaviour, mood, thoughts, or perception (Healthline, n.d.). People with PAE may respond differently to psychotropic medications. This is because of alcohol's impact on the brain and its wiring (Mela et al., 2020). Numerous people with FASD are prescribed many medications at the same time. This can cause harmful side effects (CanFASD, 2020).

ND-PAE/FASD

Neurodevelopmental disorder associated with prenatal alcohol exposure and/or fetal alcohol spectrum disorder

Before looking at psychotropic medications, experts recommend that interventions such as diet, exercise, sleep, family supports and social supports, functional behaviour analysis, behavioural management, and environmental modifications be used (Mela et al., 2020).

A team of experts from Canada has developed a medication algorithm (decision tree). It is for using psychotropic medications with people prenatally exposed to alcohol who are older than 18. The goal is to help avoid overmedication and side effects (Mela et al., 2020). The algorithm is currently being evaluated (Mela et al., 2020).

For people under 18, Mela et al. (2020) recommend using the algorithm guidelines only "when a multidisciplinary team-based ND-PAE/FASD diagnosis is confirmed" (p. e2). The algorithm is not to be used for children six and younger.

> The experts recommend that, except in extreme situations of risk of harm to self or others, psychotropic medications should be considered only for patients over the age of 7
>
> (Mela et al., 2020, p. e8)

More information can be found at Medication Algorithm - CanFASD.

Primary Impacts for Different Stages of Early Childhood

In babies less than a month old, prenatal alcohol exposure impacts motor and behavioural functioning (Subramoney et al., 2018). Most effects correlate positively (as one increases, the other increases) with higher levels and longer period of prenatal alcohol exposure (Subramoney et al., 2018). Babies under a month old showed:

- decreased arousal[1]
- decreased orientation[1]
- decreased habituation (adaptation)[1]
- decreased muscle tone[1]
- abnormal reflexes[1]
- increased irritability[1,2]
- sleep difficulties[1,2]
- sensitivity to light, noise, and touch[2]
- low birth weight[2]
- problems with sucking[2]
- ear infections[2]
- slow to develop[2]

([1]KnowFASD, 2018; [2]Proof Alliance)

Infants (2 to 23 months) have impacts in both the cognitive and motor domains (called 'global developmental impairments'). This may show as:

- muscle tone abnormalities[1,2]
- tremulousness (trembling) and difficult to sooth [1,2]
- oral-motor difficulties[1,2]
- delayed acquisition of motor milestones such as sitting, standing, and walking [1,2]
- delays in spoken language[2]
- poor verbal comprehension[2]
- slower information processing and attention regulation[2]

- poor emotional regulation[2]
- emotional withdrawal and minimal social monitoring behaviours[2]
- increased irritability[2]
- difficult temperament[2]
- passive behaviour and lack of social engagement[2]
- sleep difficulties[3]
- feeding difficulties related to weak sucking reflex, coordination and distracted by sensory stimuli[3] which can lead to failure to thrive
- aversion to touch, light, and sound[4]

([1]Riley & McGee, 2005; [2]Subramoney et al., 2018; [3]knowFASD, 2018; [4]Badry & Hickey, 2018)

Babies with FASD may be difficult to look after (Badry & Hickey, 2018). As they age, they generally are more adjusted to people, and may show little fear of strangers (Badry & Hickey, 2018).

For toddlers (2 to 3 years), the evidence about cognitive development is mixed. Many studies report:

- lower cognitive ability, gross and fine motor challenges[1,2]
- behavioural problems such as hyperactivity[1]
- impaired language abilities[1,2]
- poor memory[2]
- seems to have no fear[2]

([1]Subramoney et al., 2018; [2]Proof Alliance, 2015)

When children reach preschool age (4 to 5 years), reported impacts include:

- poor gross and fine motor skills
- greater negative affect
- hyperactivity
- emotional and behavioural problems
- insecure attachment

(Subramoney et al., 2018)

Other challenges for preschool children may include:

- naming things[1]
- understanding and using proper grammar[1]
- understanding meaning in words[1]
- understanding meaning in language[1]
- understanding context[1]
- understanding non verbal cues (social communication)[1]
- making transitions and changes[2,3] (prefer routines)
- learning from consequences[2]
- becoming overstimulated easily[2]
- flitting from one activity/area to another, exhibiting butterfly-like movements[3]

- more interest in people than objects[3]
- social skills[3]
- overly friendly and indiscriminate with relationships, may seek out affection[3,4,5] (which can make them vulnerable to abuse)
- inability to understand danger, often fearless[3,7]
- low tolerance for frustration and prone to temper tantrums[3]
- following directions or doing as told[3]
- short attention span[3,6]
- integrating sensory information, such as sound, touch, light, smells, movement, etc.[3]
- speech[4,5]
- poor memory[7]
- difficulties with food[8,9]
- disrupted sleep patterns[8]

([1]KnowFASD, 2018; [2]Badry & Hickey, 2018; [3]Healthy Child Manitoba, 2010; [4]Cook et al., 2016; [5]Riley & McGee, 2005; [6]Rajani, 2016; [7]Proof Alliance, n.d.; [8]Streissguth et al., 1998; [9]Werts et al., 2013; [10]Olson et al., 2007)

Executive function problems also begin to emerge. Executive functioning impacts social competence (Hanlon-Dearman et al., 2020). Challenges include lack of inhibition, cognitive flexibility, and the ability to delay gratification. These difficulties may play a key role in the adaptive functioning challenges seen in children and adolescents with PAE (Schonfeld et al., 2006; Whaley et al., 2001). They are a key factor in a child's ability to cope with the cognitive and social demands of the school environment (Subramoney et al., 2018).

In the early school years, reading and writing skills may not be noticeably delayed. Children with FASD often have problems with arithmetic, while difficulties with attention and poor impulse control become more apparent as the need for attention in the classroom increases (SNAP, 1999[*1]). Other problems include:

- difficulties with transferring knowledge from one situation to another (generalization)[1]
- challenges with memory and retention of information and learning[2,3,4,5]
- gross motor control problems (e.g., clumsy behaviour)[6]
- fine motor problems (e.g., trouble with handwriting, buttons, zippers, shoelaces, etc.)[6]
- difficulties with social skills and interpersonal relationships[7]

([1]Blackburn & Whitehurst, 2010; [2]Crocker et al., 2011; [3]Green et al., 2009; [4]Kodituwakku, 2009; [5]Streissguth, 2007; [6]Riley & McGee, 2005; [7]Healthy Child Manitoba, 2010)

[*1] This document was created as a resource for families and although it is indicated that it was created from a review of the literature, references are not always provided, and in those cases, it is not possible to know the sources of the information provided.

Impacts in social skills and relationships show as an inability to share, wait for turn, or follow rules; inappropriate, intrusive behaviour; and poor peer relations as children may prefer to play with younger children or adults instead of their peers (SNAP, 1999). Sleep disturbances also continue.

The following difficulties are generally associated with PAE and/or FASD in infancy and childhood:

- insecure attachment[1]
- sensory processing problems[2]
- challenges with adaptive behaviour including social, personal-, and community-living skills[3]
- sleep disorders[4]
- feeding difficulties[5]

([1]O'Connor et al., 1987; O'Connor et al., 2002) ([2]Carr et al., 2010; Franklin et al., 2008); ([3]Jirikowic et al., 2008); ([4]Olson et al., 2007; Streissguth et al., 1998); ([5]Streissguth et al., 1998; Werts et al., 2013)

In addition to the above mentioned, children with FASD have been reported to perform significantly more poorly than their peers in relation to information acquisition and processing (Jacobson et al., 1994), as well as overall academic performance (Kodituwakku, 2007) and mathematical problem-solving (Jacobson et al., 2010; Rasmussen & Bisanz, 2009).

The research on the key challenges experienced in the early years, described up to this point, is organized into Table 8.3, to demonstrate how these challenges are expressed at different stages of development.

Table 8.3 Key Challenges from Age 0 to 6 Years

Key Challenges in the Early Years (Age 0 to 6 years)					
	Neonates (< 1 month)	**Infants (2 to 23 months)**	**Toddlers (2 to 3 years)**	**Preschoolers (4 to 5 years)**	**Early School/ Childhood (5 years & above)**
Global Developmental Impairments/Motor Deficits	Decreased arousal, orientation, and habituation Abnormal reflexes and decreased muscle tone	Global developmental impairments including delayed standing, sitting, and walking; weak muscle tone & sucking reflex	Gross and fine motor deficits	Gross and fine motor deficits	Gross and fine motor deficits
Irritability/Tremulousness	Increased irritability	Increased irritability and tremulousness	Tremulousness		
Negative Affect/Attachment Problems		Poor emotional regulation and insecure attachment	Insecure attachment	Negative affect and insecure attachment	Insecure attachment
Hyperactivity/Impulsivity/ Attention/Behavioural Problems		Attention deficits	Hyperactivity and behavioural problems	Hyperactivity, behavioural problems, and short attention spans	Impulse control problems, hyperactivity, and attention problems

	Neonates (< 1 month)	Infants (2 to 23 months)	Toddlers (2 to 3 years)	Preschoolers (4 to 5 years)	Early School/ Childhood (5 years & above)
Speech/Language/Information Processing		Delays in speech, language, and information processing	Impaired language abilities	Impaired language abilities	Difficulty with information acquisition, information processing, memory, and generalizing
Sleep Difficulties		Sleep difficulties	Sleep difficulties	Sleep difficulties	Sleep difficulties
Feeding Difficulties		Feeding difficulties and 'failure to thrive'	Feeding difficulties	Feeding difficulties	Feeding difficulties
Adaptive Function Deficits/Sensory Problems		Sensory processing problems	Sensory processing problems	Sensory processing problems	Sensory processing problems; poor social, personal, and community-living skills
Learning/Academic/ Executive/Adaptive Function Problems				Executive function and adaptive function problems	Learning and academic problems including maths deficits
Social Skills Deficits		Lack of social engagement	Social skills deficits	Social skills deficits	Social skills deficits
Other Physical Health Problems* (such as impaired growth, vision and hearing problems, heart defects, seizures, weakened immune system, sleep issues, feeding difficulties, elimination concerns, and dental health)	Other physical health problems	Increased susceptibility to illness and other physical health problems	Other physical health problems	Other physical health problems	Other physical health problems

Cognitive Challenges

Cognitive functioning refers to intellectual processes and mental tasks like thinking, reasoning, and memory. Children with FASD are known to have cognitive deficits (Green et al., 2009; Howell, et al., 2006).

Every infant, child, youth, or adult living with FASD is unique but there are some common primary impacts. Cognitive challenges are often the most difficult to detect but also the most problematic.

Children impacted by PAE may show some or many of the following:

- Slower cognitive pace – needs extra time to process information[1]
- Slower auditory processing – understanding verbal information takes longer, responses may seem out of context or off topic[2,3,4]
- Reduced ability to pay attention[5,6] – shorter attention span or more distractible
- Difficulty with executive functioning[5,6] – prioritizing, organizing, reasoning, planning, initiating, and following through, may start but not finish, set goals but not know how to achieve goals
- Trouble with abstract thinking – problems with math,[5,7] time, money, and emotions[8]
- Vulnerable to manipulation by other people[9]

- Problems generalizing – what is learned in one setting is not readily transferred to another, one experience does not carry over to other similar experiences, difficulty seeing a relationship between two events or connecting separate events[10]
- Difficulty with memory[5,6] – forgetful, loses items, repeats the same mistake, seems not to learn from past, does not recall events
- Trouble with problem solving,[11,12] making choices or making decisions, cannot think of possibilities or an alternative other than what is happening right then
- Confabulation – not knowing the answer to the question but responding by offering an answer to it with no intention to deceive the one asking the question[13,14]
- Inconsistent performance because of poor working memory problems and poor adaptive functioning[15]
- Impaired ability to think about time[8]
- Impaired ability to reflect on own actions – link action and consequence[16]
- Understanding cause and effect[16]
- Communication problems – speech and language problems, can repeat rules but not understand what the rule requires, responses to questions inaccurate or illogical[5,6]
- Mental health problems[17,18]
- Expressive language disorder[19]
- Receptive and expressive language[20]
- May have a lower IQ although many individuals do not have a lower IQ[6]

([1]Burden et al., 2009; [2]Stephen et al., 2012; [3]Simões et al., 2016; [4]McLaughlin et al., 2019; [5]Cook et al., 2016; [6]Riley & McGee, 2005; [7]Rasmussen & Bisanz, 2009; [8]Greenbaum et al., 2009; [9]Clark et al., 2004; [10]Blackburn & Whitehurst, 2010; [11]McGee et al, 2009b; [12]Stevens et al, 2012; [13]Brown et al., 2013; [14]Koren & Ornoy, 2020; [15]O'Malley, 2007 as cited in Blackburn & Whitehurst, 2010; [16]Goswami & Bryant, 2007 as cited in Blackburn & Whitehurst, 2010; [17]Astley, 2010; [18]Pei et al., 2011; [19]Popova, Lange, Shield et al., 2016; [20]Shaywitz et al., 1981; Tenbrinck & Buchin, 1975 as cited in Blackburn & Whitehurst, 2010)

Adverse Impacts of FASD

Besides the primary impacts of FASD, children with FASD are at high risk of developing adverse impacts (previously known as secondary disabilities, impacts, conditions, or challenges). These adverse impacts may include mental health conditions, addictions, and behavioural challenges. Adverse impacts will be discussed in more detail in module 9.

Many factors interact with the primary disabilities experienced, to determine whether a child will develop adverse impacts. These include individual, family, and system/community factors.

Some of these factors may be protective. Protective factors promote the development of skills or adaptive functioning. This can help reduce the possibility of adverse impacts (Petrenko et al., 2019). Protective factors include:

- early diagnosis (before the age of six)
- receipt of relevant support services

- obtaining a diagnosis of FASD
- a stable and nurturing home environment
- absence of violence or maltreatment

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

Specific family-level risk and protective factors include:

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

(Olson et al., 2009)

Addressing each of the factors described above can increase the protective factors experienced by the child, and thereby help to reduce the occurrence of adverse impacts. The section on behavioural management strategies describes in detail particular primary impacts that a child may experience and strategies that can be implemented to reduce or prevent the occurrence of related adverse impacts.

Primary Impacts and Promising Strategies

In this section, the key issues/challenges observed in the early years are discussed in greater detail, followed by the strategies that can be implemented by those supporting the children in the community. This includes parents, other caregivers, and educators. The goal of these strategies is to prevent or reduce adverse impacts that can result from an interaction between the primary disabilities experienced and the environment the child develops in. When general caregiver strategies are not available in the research literature, potentially relevant programs and interventions are described to provide possible strategies to use.

Executive Functioning (EF)

Executive function refers to higher-order cognitive processes that require complex thought practices and behaviours, such as planning, organizing, sequencing, and other forms of abstract thinking (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2000). Executive functioning has been recognized as an important impact in individuals with FASD (Cook et al., 2015; Kodituwakku, 2009). There may be problems with personal-care and independence (e.g., routine activities that require a sequence of steps, such as getting dressed) (NIAAA, 2000). Executive functioning is related to the ability to understand the perspective of other people (Rasmussen et al., 2009). It is also related to predicting social skill impacts in children with FASD (Green et al., 2009). EF is also related to:

- inhibition
- verbal fluency
- abstract thinking
- deductive reasoning
- hypothesis testing
- problem solving
- concept formation
- working memory

(Rasmussen & Bisanz, 2009)

Strategies for Executive Function Impacts

In literature, there are no general caregiver strategies to manage the limitations of executive functioning. However, some programs and interventions using neurocognitive habilitation have been shown to be promising in improving executive functioning, problem-solving skills, and self-regulation (Bertrand, 2009; Wells et al., 2012).

Neurocognitive habilitation is a group treatment model that teaches children to recognize their challenge areas and develop strategies to compensate while building on existing skills and strengths (Wells et al., 2012). This treatment model was developed from the combination of techniques and interventions used in therapy for traumatic brain injury (Dykeman, 2003) and from components of the Alert Program (Williams & Shellenberger, 1996). The Alert Program is a curriculum that helps children improve self-regulatory skills. The neurocognitive rehabilitation program involves both children and caregivers and incorporates program elements such as group learning activities, repetition of activities to facilitate memory consolidation, as well as goodbye rituals (Wells et al., 2012).

Information Acquisition/Processing

Individuals with FASD experience impacts in both the quantity and the quality of the information they can process (Burden et al., 2009; Jacobson et al., 1994). When presented with the same amount of information, children with FASD usually acquire less information than typically developing children (Mattson & Roebuck, 2002; Roebuck-Spencer & Mattson, 2004). Challenges with information processing mean that the functional link between understanding the information supplied and performing the appropriate action required is flawed (SNAP, 1999). Four aspects of information processing which are impacted are:

- cause and effect – the ability to translate information to corresponding action as well as link action and consequence[1]
- generalization – the ability to apply information from one context to another situation[2]
- sorting, classification, inference, and abstraction – the ability to recognize and distinguish between people, places, things, and events[3]
- prioritization, prediction, production, and sequencing[3]

([1]Goswami & Bryant, 2007 as cited in Blackburn & Whitehurst, 2010; [2]Blackburn & Whitehurst, 2010; [3]Morse, 1993, as cited in SNAP, 1999)

Strategies for Information Acquisition/Processing Impacts

Research has shown that children with FASD can successfully learn new information when they are given more time and with consistent repetition (Engle, 2008; Simmons et al., 2006). Two promising strategies to manage challenges with information acquisition and processing are individualized instruction and semantic clustering.

In a study by Duquette and colleagues (2006), individuals with FASD reported that they learned new information better when it was taught and re-taught in small amounts, as well as when learning was hands-on or modeled. It is also recommended that teachers individualize their instruction by slowing

down the pace of their instruction while also providing supports to enhance concept formation for individuals with FASD (Simmons et al., 2006). Classroom tips for teachers to assist with information processing and memory deficits include allowing extra classroom time to process information and take tests; and teaching students how to "self-talk" as this helps them remember routines and problem-solve (Zieff & Schwartz-Bloom, 2008). Information overload should also be avoided, as well as any form of external stimulation or distraction (Zieff & Schwartz-Bloom, 2008).

Semantic clustering is another strategy that is effective in helping children with FASD learn new information (Roebuck-Spencer & Mattson, 2004). As the name implies, it is a way of grouping words into categories; for example, apple, banana, and orange can be clustered under the category 'fruit' (Riggie & Xu, 2013). This grouping can help individuals with FASD connect words and their meanings and makes information retrieval easier when prompted with the clustering category (Riggie & Xu, 2013).

Speech, Language, and Communication

Language and speech difficulties have been reported in children with heavy prenatal alcohol exposure. This includes:

- delays in speech acquisition (Church & Kaltenbach, 1997)
- impaired receptive and expressive language (Church & Kaltenbach, 1997; McGee et al., 2009a)
- issues with speech production (Mattson & Riley, 1998)

Another school of thought believes that children with FASD can acquire basic language skills in a typical manner, but may, later in life, experience difficulties communicating socially as well as with higher-order language skills such as complex syntax, metacognitive abilities (awareness and understanding of one's thought processes), and narrative skills (Coggins et al., 2003).

<u>Strategies for Speech, Language, and Communication Difficulties</u>

A common approach to the management of speech and language deficits is to refer to a speech-language therapist (Olson & Montague, 2011). However, an important part of intervention may be to watch the developmental progress of the child and provide anticipatory guidance for parents and teachers for the possibility of subtle language and social communication deficits that may occur as children grow older (Olson & Montague, 2011). Also, parents of children with FASD suggest the use of constant reminders, rephrasing, and repetition of the correct pronunciation of words as promising practices (St. Michael's Fetal Alcohol Spectrum Diagnostic Clinic, n.d.).[b2]

Attention and Memory

It is well documented that children with FASD have attention and memory deficits (Green et al., 2009; Kodituwakku, 2009; Streissguth, 2007). They struggle with focusing and engaging attention (Mattson et al., 2006), as well as shifting their attention from one topic to another (Coles et al., 1997). Memory problems generally impact verbal, visual, and working memories (Manji et al., 2009). Crocker et al.

[b2] This document is a compilation of strategies that have worked for individual families, to inspire other families of children with FASD. It should be noted that this is not a peer-reviewed source.

(2011) reported that children with heavy prenatal alcohol exposure demonstrated poor recognition and retention of information that had been previously taught.

Strategies for Attention and Memory Challenges

There are no specific caregiver strategies for memory and attention difficulties in children with FASD. However, rehearsal training as a formal intervention has been shown to be promising. In their study, Loomes et al. (2008) examined the effectiveness of verbal rehearsal training on the working memory of children (aged 4 to 11) with FASD and observed that it was successful in increasing their memory for numbers. In the study, rehearsal training included behaviours such as whispering, moving lips, or saying the stimuli repeatedly. This finding suggests that verbal rehearsal training may help to reduce working memory difficulties in FASD and ultimately reduce academic and developmental challenges (Loomes et al., 2008).

Visual-Spatial Function

Visual-spatial functioning is the ability to see objects and understand their spatial relationships (NIAAA, 2000). Children with prenatal exposure to alcohol have been shown to have several visual-spatial challenges (Uecker & Nadel, 1996). Challenges include:

- problems with basic figure copying[1]
- spatial-visual memory[2]
- spatial working memory[3]
- spatial recall[4]
- visual-spatial reasoning[5]
- visual-perceptual matching (e.g., matching complex geometric shapes)[6]

([1]Conry, 1990; [2]Streissguth, 2007; [3]Green et al., 2009; [4]Willoughby et al., 2008; [5] Hunt et al., 1995; [6]Janzen, Nanson, & Block, 1995)

Strategies for Visual-Spatial Function Impacts

Strategies for visual-spatial challenges are not common in literature. Some ways teachers manage this difficulty in a classroom environment include ensuring visually clear display and using tape on the floor to define spatial boundaries (Carpenter, 2011). To help with spatial direction and organization in the classroom, using visual and verbal cues such as a highlighter to help the student know where to begin an activity may be helpful, as well as a graph paper for maths and numeracy tasks (Zieff & Schwartz-Bloom, 2008).

Learning and Academic Performance

Prenatal alcohol exposure has been demonstrated to be related to overall academic performance. This includes difficulties in reading, spelling, and arithmetic (Goldschmidt et al., 1996). Teachers have also been able to identify some problem behaviours exhibited by children in the classroom that impacts their overall learning and academic performance. Such problem behaviours include:

- hyperactivity
- short attention span

- erratic mood swings
- poor retention of instruction
- lack of social skills
- poor memory skills
- auditory and vocal processing problems
- visual sequencing problems
- lack of coordination (i.e., sensory integration difficulties)
- mathematical/numeracy difficulties

(Carpenter, 2011)

Strategies for Impacts Related to Learning and Academic Performance

In addressing the classroom-related problems of children with FASD, several adjustments can be made which include:

- maintaining a calm learning environment, free from clutter
- presenting focused tasks in small steps
- giving the student personal space with plenty of support and praise
- visual structuring
- scripting/role-playing
- providing short, key information-carrying word instructions
- using clear visuals and simple graphics
- taking frequent, short exercise activities during the day
- breaking down of tasks with visual and tactile clues, and giving sufficient time for the child to complete the task
- providing opportunities for multisensory learning (i.e., giving messages through a variety of sensory pathways).

(Carpenter, 2011)

Teachers also observed that children with FASD are visually dominant learners and strategies that support this attribute should be incorporated in the learning environment. Strategies include:

- seating the child at the front of the classroom, in the same seat
- reducing distractions
- providing a calm space
- ensuring visually clear display
- using tape on the floor to define spatial boundaries
- keeping the classroom door closed
- closing blinds to reduce light brightness
- avoiding bells

(Carpenter, 2011)

Mathematics/Numeracy

According to a review by Rasmussen & Bisanz (2009), several studies have reported the presence of significant math challenges for children with PAE and FASD. Evidence also suggests a positive relationship between math difficulties and the amount of prenatal alcohol exposure in children with FASD (Rasmussen & Bisanz, 2009).

Children with FASD are likely to experience challenges with mathematics more than other cognitive areas (Rasmussen & Bisanz, 2009). Since math and numeracy skills are very important at school and in daily life, early intervention is important. The student with FASD may have mathematically related difficulties such as:

- poor understanding of what a number is and its significance
- difficulty with basic math skills (relying more on calculator or fingers)
- confusion with math symbols and vocabulary
- spatial difficulties in knowing where to begin working on a problem (left to right/right to left)
- confusion when different math terms are used for the same concept (e.g., 'addition', 'total', 'sum', 'all together', 'in all')
- being overwhelmed by too much on a page
- confusion as to when to use a math operation or concept
- inability to read, understand, or solve word problems
- difficulty with number sequencing

(Zieff & Schwartz-Bloom, 2008)

<u>Strategies for Mathematical/Numeracy Challenges</u>

A promising practice is the use of an educational assistant to support the child in the classroom during learning sessions (Carpenter, 2011). Some other strategies for improving mathematical skills include:

- using objects/manipulatives to introduce basic math facts (e.g., use art to create numbers that students can see and feel – decorate with glitter, noodles, yarn, etc.)
- using a number line, fingers, or anything that works
- relating math facts to student's life experiences
- using multi-sensory and memory aiding approaches such as singing or chanting math facts; saying a fact aloud, writing the fact, and then reading the fact; using computer programs or calculator
- keeping a simple layout and reduce the number of math problems on a page; this reduces frustration, as well as visual distraction
- putting the same types of problems on one page (e.g., only addition) and as the student becomes proficient, gradually add new problems to the page
- practicing math daily for short periods
- teaching math at a slow pace
- allowing extended time on tests or assignments
- using consistent math vocabulary
- using processing cards and checklists to assist with sequencing and break down calculations in a step-by-step format

- using visual (e.g., highlighter) or verbal cues in the classroom to help the student know where to begin tasks where there is confusion regarding left/right
- using graph paper to help with spatial organization

(Zieff & Schwartz-Bloom, 2008)

Motor Function

Several human and animal studies have demonstrated the impact of PAE on the development of motor functions. Motor functions direct voluntary movement (NIAAA, 2000; Subramoney et al., 2018). Motor control is a complex function managed by the central nervous system (CNS). The CNS receives signals from the sensory organs, such as the eyes, ears, and skin; and the vestibular system (involved in balance) (NIAAA, 2000). Motor skill impacts can be grouped into difficulties in:

- fine motor skills (e.g., difficulties with handwriting, buttons, zippers, and shoelaces)
- gross motor skills (e.g., walking and balance)

(Olson & Montague, 2011; SNAP, 1999)

Early problems with motor control in infants with PAE may show as tone abnormalities, tremulousness, oral-motor difficulties, and delayed acquisition of motor milestones (Riley & McGee, 2005; Subramoney et al., 2018). Delay in motor milestones also includes delayed sitting, standing, and walking as seen in infants with FASD between 6 and 18 months (Subramoney et al., 2019).

<u>Strategies for Motor Function Challenges</u>

Developmental therapies, such as motor training with established learning criteria administered by qualified therapists, are some of the professional interventions (Olson & Montague, 2011). Allowing the child to spell verbally to avoid the fine motor struggles of writing/printing, as well as using different tools for printing/writing such as chalk on a sidewalk, finger painting on paper, or a stick in the sand are some strategies used by caregivers (St. Michael's Fetal Alcohol Spectrum Diagnostic Clinic, n.d.).

Behavioural Disabilities

Human behaviour is highly variable and includes an assortment of actions, reactions, and voluntary and involuntary activities all controlled by brain function. Much behaviour is related to social and emotional development and is visible through social and emotional interactions.

Because brains are responsible for behaviours, an affected brain with impairments in information processing will produce impaired and disordered behaviours. There are a variety of disabling behaviours associated with FASD (Chudley et al., 2005). These behaviours are the visible signs of the physical injury to the brain. The behavioural disabilities, just like the cognitive and physical disabilities, influence and impact one's ability to meet the expectations of the real world or perform the necessary tasks of daily life.

Inaccurate Processing → **Disordered Behavioural Responses**

Some examples of behavioural problems experienced by children, youth, or adults with FASD are:

- Problems with social interactions (establishing reciprocal peer relationships)[1,2,3]
- Impaired ability to read social cues – cannot detect subtle, or even obvious, social cues such as body language and have disordered responses[4]
- Impulsive actions, does things without thinking, and poor ability to delay gratification,[5,6] lives in the moment and wants immediate results
- Lack of inhibitions[5] – may be overly friendly or too direct in approaching others
- Poor understanding and use of personal boundaries and personal space[7]
- Stealing or giving away valuable possessions[8] because ownership is an abstract concept
- Struggles with regulating emotions[9] – unpredictable mood swings, anger, explosiveness, may appear to be emotionless, violence possibly triggered by seemingly minor events
- Poor ability to express empathy[10,11,12] – differences in bonding and attachment
- Perseveration[6] – getting stuck on an issue, idea, or place; extreme focus; rigid and inflexible behaviour patterns
- Poorer social problem-solving skills than their non-exposed peers[13]
- Dysmaturity (acting young for age)[5]
- Inability to see another person's perspective[14]
- Unable to predict outcomes[14]
- Impulsivity and poor judgement[14]
- Sleep problems – seems to sleep too much or not enough, lacking an internal clock, disordered sense of time[15]
- Being over-active[6] – inability to self-calm or regulate energy levels
- Difficulty with starting and continuing tasks[5]
- Difficulty concentrating, and cannot pay attention for long[5]
- Disobedient at home[5]
- Confabulation (often seen as lying)[5,16]
- Lacks guilt after misbehaving[5]
- Difficulty sitting still/is restless/hyperactive[5]
- Intensity of negative moods[17,18]
- Difficulty planning and carrying out motor actions (e.g., clumsiness)[19]
- Easily overwhelmed and may shut down entirely as a response[19]
- Change and transitions in activities or plans are hard – may react badly to changes in routine[20]

([1]Bishop et al., 2007; [2]Stevens et al., 2017; [3]Blackburn & Whitehurst, 2010; [4]Greenbaum et al., 2009; [5]Koren & Ornoy, 2020; [6]Riley & McGee, 2005; [7]SNAP, 1999; [8]Nash et al., 2006; [9]Subramoney et al., 2018; [10]Rasmussen et al., 2009; [11]Stevens, 2012; [12]Stevens et al., 2015; [13]McGee et al., 2008; [14]Centre for Addiction and Mental Health [CAMH], 2020; [15]Wengel et al., 2011; [16] Brown et al., 2013; [17]O'Connor, 2001; [18]Haley et al., 2006; [19]Lane et al., 2000; [20]Badry & Hickey, 2018)

Attention, Hyperactivity, and Impulsivity

Challenges with attention, hyperactivity, and impulsivity can all contribute to behavioural disabilities. The degree of prenatal alcohol exposure has been associated with the degree of distractibility and the reaction times of children with FASD on performance tasks (Kodituwakku, 2007). As well, children with FASD are likely to have poor attention spans (Aragón et al., 2008; Carpenter, 2011), and act impulsively and restlessly (Carpenter, 2011; Janzen et al., 1995; Rasmussen et al., 2010). May also meet the diagnosis requirements for ADHD (Fryer et al., 2007). Approximately 50% of people with FASD have ADHD. This is 10 times more prevalent than in the general population (Weyrauch et al., 2017). Impulsivity, which is a common trait in children with FASD (Rasmussen et al., 2010), is usually a safety concern for many parents (Burgess & Streissguth, 1992) as children have a hard time understanding the relationship between cause and effect or foreseeing the long-term consequences of their actions (SNAP, 1999).

<u>Strategies for Challenges in Attention, Hyperactivity, and Impulsivity</u>

Some strategies reported by parents to manage difficulties with attention and hyperactivity are listed below (SNAP, 1999; St. Michael's Fetal Alcohol Spectrum Diagnostic Clinic, n.d.):

- Allow children to focus on what interests them.
- Avoid trying to make the child concentrate for long periods.
- Keep instructions simple, gradually increasing the amount of time spent on a task (e.g., starting at 1 minute and going to 10 minutes).
- Use a visually boring place for tasks that require focus (e.g., getting dressed).
- Limit TV and avoid video games if this causes the child to become overstimulated.
- Alternate activities requiring attention (e.g., studying, washing dishes, etc.) with physical activity (e.g., running, dancing, etc.).
- Ensure the environment is calming and avoid clutter (e.g., play calm instead of energetic music).
- Avoid situations where the child may be overstimulated by light, movement, sound, colour, toys, noise, activities, or crowds (e.g., birthday parties).
- Make sure extracurricular activities do not cause overstimulation, such as pillow fighting or wrestling.
- Designate a calm and comfortable place for "quiet time" where the child can go when they are overwhelmed; making it clear that "quiet time" is not a punishment.
- If anger is a problem, have a safe place for the child to express it in some physical manner (e.g., kicking a ball).

Additional strategies for impulsivity include the following (SNAP, 1999):

- Teach the concept of "your turn" by using a physical object such as a "talking stick".
- Teach children to walk and not run by counting numbers between steps.
- In a calm and consistent manner, verbally point out and correct impulsive behaviour as early as possible (i.e., from toddlerhood).
- Avoid and anticipate impulsive moments and step in as soon as possible.
- Allow a tantrum to run its course and help the child to calm.

- If time out is needed, consistently use the same designated place (preferable calm and not cluttered). Avoid places used for other important or fun activities.
- Teach simple terms with visual cues to help the child "look before they leap".
- Limit choices, as a variety of options can cause intense frustration and impulse control problems.
- Always have a back-up plan, as one strategy may not work on every occasion.

Functional/Adaptive Skills and Sensory Processing

Children with FASD have poor adaptive skills which are usually significantly lower than expected for their age and intellectual level (Streissguth et al., 2004). Challenges with adaptive skills increase with age and include difficulties in:

- daily living skills (also known as activities of daily living, such as mealtimes, dressing, and toileting), communication, and social skills (Olson & Montague, 2011; Whaley et al., 2001)
- sensory processing (Carpenter, 2011; Carr et al., 2010)
- sensory regulation (Brown et al., 2010; Carpenter, 2011)
- vocational skills in young adults (Spohr et al., 2007)

The sensory system is an important body system that begins to develop during gestation and continues to develop throughout childhood. The human sensory system allows a child to take in information about where he is in the world and what is going on around him. The brain receives information from each sense and provides the ability to taste, smell, touch, hear, see, know body position (proprioception) and perceive movement sensations (vestibular input) (Jirikowic, 2007).

Sensory processing is "the way a person detects, regulates, interprets, and responds to sensory stimuli and has both physiological and behavioural components" (Ben-Avi et al., 2012, p. 70). Typical sensory processing enables adaptive and organized reactions to environmental stimuli, while atypical patterns of sensory processing may negatively impact the functioning of an individual in everyday life (Ben-Avi et al., 2012).

Sensory issues are common for children impacted by PAE. While more research is needed in this area, families have recognized a range of sensory impairments resulting from prenatal alcohol exposure. Sensory impairments are often noticeable during infancy and continue throughout the lifespan (Jirikowic, 2007)

Research suggests that sensory processing impacts children with neurodevelopmental disabilities differently (Dunn et al., 2016). High rates of sensory processing problems (80% to 88%) have been reported in clinical samples of children with FASD (Carr et al., 2010; Franklin et al., 2008; Jirikowic et al., 2008). Some common behavioural displays of sensory processing problems include:

- inattention/distractibility
- hyperactivity
- emotional dysregulation
- clumsiness
- motor and behavioural disorganization

(Jirikowic, 2007)

Sensory processing difficulties have also been found to co-occur with:

- problem behaviours[1]
- lack of adaptive behaviours (i.e., age-appropriate behaviours necessary to live independently and function safely)[2]
- poorer academic performance
- sleep problems[3]

([1]Franklin et al., 2008; [2]Jirikowic et al., 2008; [3]Wengel et al., 2011)

Sensory processing and integration enable successful functioning, responding, and making sense of the world. When a brain has been impacted by prenatal alcohol exposure, individuals may experience a variety of sensory issues and sometimes are diagnosed with a sensory integration disorder. Disordered sensory processing and integration can create a variety of difficulties for individuals with FASD and can impair learning, physical functioning, and behavioural development (Jirikowic, 2007).

A study published in the *American Journal of Occupational Therapy* (Franklin et al., 2008) confirms that a link clearly exists between sensory processing difficulties and problem behaviours in children with FASD. The article suggests that occupational therapists should address the sensory processing concerns identified in children with FASD and by doing so, the intervention will offer the possibility of decreasing the often-confusing behaviours of children with FASD.

Signs and Symptoms of Sensory Impacts

- Sensory Sensitivities (increased or decreased) to one or more of the five senses (i.e., sight, hearing, taste, smell, and touch)[1,2]
- Over-reactive to stimuli (hypersensitivity) – unable to filter out varying forms of sensory input, difficulty knowing which sensory messages are important or unimportant[1,2]
- Under-reactive to stimuli (hyposensitivity) – brain does not seem to focus on any one type of stimuli, shows little reaction to sensory input[1]
- Sensory seeking behaviours or sensory avoidant behaviours[2] e.g., an aversion to touch[1]
- Difficulties with sensing self in space and controlling movement[1]
- Sensory integration problems or sensory processing problems[2]
- Unusually high (slow to settle down) or low activity level (shuts down)[3]

([1]Cook et al., 2016; [2]Jirikowic, 2007; [3]Riley & McGee, 2005)

The sensory system begins to develop during gestation and continues to develop throughout childhood.

Table 8.4 shows the impacts on the senses reported by adults with FASD in the survey done by Himmelreich et al, 2020.

Table 8.4 Sensory Impacts of FASD

Disease/Disorder/Condition	General Prevalence	FASD Frequency (%)
Do not feel pain the way others do – High pain tolerance for major things		53.1
Feel more pain than others do even for minor things		33.6
Don't like tags, wrinkles, socks, etc.		74.8
Clothes need to be very tight		16.1
Clothes need to be very loose		46.0
Don't like loud noise (hyperacusis)		63.4
Cannot tolerate bright light		57.5
Difficulty feeling temperature (hot or cold) like others do		54.1
Difficulty regulating temperature (go from too hot to too cold quickly and often)		49.9
No sense of smell		10.1
Disordered sense of smell (things smell different than to others (dysomia)		28.3
Poor or no sense of taste for many foods (hypoaguesa or aguesa)		10.9
Do not like texture of some/many foods		58.2
Really like spicy hot foods (can taste)		39.1
Like to eat lemons		33.1
Do not feel hunger much		36.6
Skin is very sensitive to stimuli		52.2
Skin itself (not muscles) hurts with use		16.3
Easily overwhelmed (panicky) by crowds, large groups (noise, light, movement, touch)		75.7
Over-reactive to some body sensations and under-reactive to others		68.6

Source: Lay of the Land: FASD as a Whole Body Diagnosis in The Routledge Handbook of Social Work and Addictive Behaviours (Himmelreich et al., 2020, pp. 289-290)

Sensory processing difficulties may be exhibited as hypersensitivity (having a lower neurological threshold) or hyposensitivity (having a higher neurological threshold) to senses of touch, taste, smell, sight, and sound (Ben-Avi et al., 2012; Dunn, 2001). Hypersensitivity is the tendency to have a negative reaction to sensory stimuli that are usually considered harmless. Such individuals are easily distracted by movements, sounds, or smells while around people, such as in a class or at the movie theatre (Dunn, 2001). They also easily "notice food textures, temperatures, and spices quicker than others and may be uncomfortable with clothing tags, elastic, or certain fabric textures" (Dunn, 2001, p. 612).

On the other hand, hyposensitivity is the decreased sensitivity to sensory stimuli in the environment (Ben-Avi et al., 2012). Such children have difficulty feeling things and exhibit symptoms such as the

inability to feel hot or cold, as well as high pain thresholds. They also show outcomes such as inattention to injuries, and behaviours such as excessive touching and increased activity (Ben-Avi et al., 2012; Developmental Services Resource Centre Waterloo Region, n.d.).

Children with sensory processing difficulties may be so focused on what they hear, see, or feel that they are unable to focus on other things (Developmental Services Resource Centre Waterloo Region, n.d.). This may cause them to shut down or "act out" in response to the stimuli, such that their behaviour increases or decreases in response to the environmental stimulus (Developmental Services Resource Centre Waterloo Region, n.d.).

Strategies for Functional/Adaptive Skills and Sensory Processing Challenges

Occupational therapists can evaluate and support adaptive function and sensory integration difficulties in individuals prenatally exposed to alcohol (Carpenter, 2011; Jirikowic et al., 2008). Studies have also shown the use of virtual reality programs as promising interventions for children on issues such as fire safety and street safety (Coles et al., 2007; Padgett et al., 2006). The virtual reality program uses multiple modalities (visual, spatial, auditory, and physical activity), helping subjects to generalize their learning to the real world.

In vivo instruction is another promising strategy. It is a process in which students are taught and coached on a particular skill in the context of their natural environment so that students can apply skills they have learned in their everyday lives (Riggie & Xu, 2013).

Sensory integration and exercise programs have been identified by teachers as practices that should be considered for children with FASD (Carpenter, 2011). Sensory integration is a theory/framework that helps with understanding and learning and addresses behavioural difficulties in children with neurodevelopmental challenges (Jirikowic, 2007). It is one of the several frameworks used by occupational therapists and other professionals. It can be conducted using standardized tests that measure sensory integrative functions or through informal observation of the child's movement, play, and social interaction across different environments (Jirikowic, 2007). This gives important insights as to how the child responds to sensory stimulation and how it impacts their adaptation, behaviour, and skills (Jirikowic, 2007).

For activities of daily living such as dressing, the following strategies are suggested (Zieff & Schwartz-Bloom, 2008):

- Put entire outfits together on individual hangers in the order they go and teach the child to put on clothes in the same order.
- Teach the child to button from bottom to top to help "see" the match better. Try Velcro instead of buttons.
- Teach how to tie shoelaces, or use Velcro, elastic coil laces that do not require tying, or try slip-on shoes instead.
- Have an extra supply of clothing and accessories that are likely to go missing.

Similarly, structure and routine should be maintained during bath times.

- Keep all personal grooming aids together in a container. Assign a colour to the child.
- Post bathroom routines, using simple words with pictures.
- Put in place safety measures (e.g., a colour code system for hot and cold taps, a timer on the shower that shuts it off, a line drawn on the bathtub to prevent the child from overfilling the bath).

Strategies for mealtimes are listed under strategies for feeding difficulties.

Strategies for sensory processing difficulties may be visual, auditory, oral, or olfactory (smells/scents) oriented, as well as those that address tactile/rhythmical movements and vestibular/proprioceptive (balance and orientation) sensory processing (Fjeldsted & Hanlon-Dearman, 2009). It is recommended to first observe what the child is reacting to and take the necessary precautions (Developmental Services Resource Centre Waterloo Region, n.d.).

Visual strategies may include dimming the lights in a room or having sunglasses on hand when going out if the child is hypersensitive to light (Developmental Services Resource Centre Waterloo Region, n.d.). For a child who is hypersensitive to noise, keeping headphones on hand, turning down the radio volume, or going to the mall at quiet times of the day could be helpful (Developmental Services Resource Centre Waterloo Region, n.d.).

Children with tactile sensitivity may benefit from having clothing tags removed, washing new clothing before wearing, and using soft bedding. For children who are hyposensitive and need to be constantly stimulated, the use of fidget items such as a stress ball, bean bag, toy, or something bendable or twistable can help the child to stay calm and focus more readily (Developmental Services Resource Centre Waterloo Region, n.d.). Slow rhythmical linear movements, such as in a rocking chair, can be calming, while fast movements in various directions (e.g., running or spinning) can cause overstimulation (Fjeldsted & Hanlon-Dearman, 2009).

Common scents in the home (e.g., from laundry soap, fabric softener, toothpaste, body soap, or lotions) can be overwhelming for children with FASD and are best avoided. Scents that are calming for the child (e.g., vanilla, banana, or lavender) are recommended (Fjeldsted & Hanlon-Dearman, 2009). Since sensory processing is linked with many other issues experienced by children with FASD, strategies to manage sensory processing impacts are further examined in relation to other key difficulties discussed in this module.

Social Skills and Emotional Regulation

Studies have shown that social problems become more pronounced as children with FASD grow older (Thomas et al., 1998; Whaley et al, 2001). One important factor suggested to be responsible for this is social cognition. Social cognition is a key ability that is compromised in individuals with FASD (Greenbaum et al., 2009). Social cognition has to do with thoughts and beliefs about self, others, and the

social world (Miller, 2010). Generally, it relates to specific aspects of people (e.g., thoughts, desires, emotions), as well as social groups and social institutions (Miller, 2010).

Children with FASD typically show a wide range of social cognition difficulties such as:

- emotion recognition[1]
- social perspective-taking which is also known as the theory of mind (the ability to understand the mental states of others) and empathy[2]
- social information processing/problem solving[3]
- moral reasoning[4]
- processing of emotions from facial expressions[5]

([1]Greenbaum et al., 2009; Kerns et al., 2015; Rasmussen et al., 2009; Stevens et al, 2017) ([2]Rasmussen et al., 2009; Stevens, 2012; Stevens et al., 2015) ([3]McGee et al., 2009b; Stevens et al., 2012) ([4]Schonfeld et al., 2005) ([5]Kerns et al., 2015; Stevens, 2012)

Challenges with social skills in children with FASD have also been directly linked to cognitive variables. Authors suggest that these variables likely interact with environmental factors to produce the spectrum of social deficits observed in FASD. Cognitive variables can include:

- executive functioning[1]
- language[2]
- sensory processing issues[3]

([1]Schonfeld et al., 2006) ([2]McGee et al., 2009b; Olswang et al., 2001) ([3]Carr et al., 2010; Franklin et al., 2008; Jirikowic et al., 2008)

Social skill impacts may be shown as difficulty in developing and maintaining relationships (Thomas et al., 1998); difficulty with appropriate social behaviours and communication; or being overly friendly or uninhibited (Bishop, Gahagan, & Lord, 2007). Children with FASD may also have a hard time getting along with peers and may experience teasing (Mattson & Riley, 2000). This can lead to psychosocial problems and social withdrawal.

A variety of social-emotional challenges are also shown as internalizing and externalizing behaviours (Graham et al., 2012; Greenbaum et al., 2009; Tsang et al., 2016). Internalizing behaviours are harm-causing emotional behaviours directed inwardly towards the individual exhibiting them rather than others (Rasmussen et al., 2010). Common internalizing behaviours for children with FASD include:

- depression[1,2]
- being anxious, withdrawn, and having somatic complaints[2]
- lack of persistence, forgetfulness, and confusion[3]

([1]O'Connor & Paley, 2006; [2]Tsang et al., 2016; [3]Graham et al., 2012)

People with FASD have much higher rates of anxiety and depression. Anxiety occurs at 11 times the rate in the general population (Weyrauch et al., 2017). Depression is four times that experienced in the general community (Weyrauch et al., 2017).

Externalizing behaviours are directed outward. They are likely to be disruptive, and cause harm to other people (Riggie & Xu). Individuals with FASD have been found to exhibit a variety of these behaviours, including:

- rule-breaking and aggressive behaviour[1]
- hostile behaviour[2,3]
- mood swings[4]
- lying and stealing[5]
- substance abuse[6]
- inappropriate sexual behaviours[6,7]
- trouble with the law[6,7]

([1]Tsang et al., 2016; [2]Keil et al., 2010; [3]O'Connor & Paley, 2009; [4]Carpenter, 2011; [5]Nash et al., 2006; [6]Burd et al., 2003; [7]Streissguth et al., 2004)

Strategies for Social Skill Challenges and Emotional Regulation

Promising strategies to improve social skills and social behaviour in children with FASD include social skills training and socio-behavioural therapy (Riggie & Xu, 2013). Social skills training involves providing rules of social behaviours; modeling/role-playing appropriate behaviours; rehearsal at home; coaching by the parent during playtime with a peer; and giving home assignments (Bertrand, 2009).

Appropriate social skills that can be taught include:

- how to share and take turns
- how to ask for help
- how to interpret such things as facial expressions, tone of voice, and posture
- how to make choices
- how to ask others if they can join in an activity
- how to say "No"

Behaviours that are considered inappropriate, such as standing too close, interrupting and talking non-stop, throwing things, and not asking for help can also be taught (SNAP, 1999). Teach social skills consistently and repetitively and keep each lesson brief (SNAP, 1999).

Socio-behavioural therapy, on the other hand, involves providing training, coaching, and support to parents, as well as teaching them behavioural management skills (Bertrand, 2009; Riggie & Xu, 2013). This form of caregiver-focused therapy has been found to complement social skills training/intervention for children with FASD (Bertrand, 2009). Parents and caregivers have also reported improved knowledge about FASD and FASD-related parenting issues after undergoing this therapy.

Other strategies for socio-emotional challenges include the use of reinforcement as a behavioural support tool for caregivers (Carpenter, 2011; Engle, 2008), provided that the expectations and rewards remain consistent (Carpenter, 2011). Function-based interventions have also been successful in reducing challenging behaviour in children with FASD (Kurtz et al., 2008). This approach has been used with

people with intellectual disabilities. It involves an initial direct observation of challenging behaviour (functional analysis) which helps to identify specific environmental factors that may reinforce challenging behaviour, before appropriate intervention can be established (Kurtz et al., 2008). Environmental factors may include adult attention, access to physical items, and non-preferred tasks.

Lastly, evidence suggests that teaching strategies to improve self-regulation through an intervention process known as neurocognitive habilitation also has the potential to improve social cognition in children with FASD (Wells et al., 2012). Neurocognitive habilitation was described previously in the section discussing Executive Function challenges.

Sleep & Sleep Disruptions

Sleep is essential in maximizing neurodevelopmental potential and overall well-being (Hanlon-Dearman et al., 2018). Good quality sleep, especially night time sleep, helps children with full daytime alertness (Hale et al., 2009). Clinical sleep disorders are often associated with developmental disabilities, including difficulty falling asleep, frequent night awakenings, and abnormal sleep patterns (Stores, 1999; Wengel et al., 2011).

Sleep disruption has been identified as a clinically important symptom of FASD, and has many negative effects on the child's health, adaptive function, and on family and caregiver's sleep (Streissguth, 1998; Wengel et al., 2011). It has been suggested that the prevalence of sleep disruption may be comparable to that of hyperactivity (an important clinical feature of FASD) in children with FASD (Streissguth et al., 1998). Studies have reported the prevalence of sleep problems in children with FASD to be as high as 85% (Chen et al., 2012).

Sleep problems in children with FASD are often comprehensive and include:

- increased bedtime resistance
- reduced sleep duration
- sleep anxiety
- night awakenings
- parasomnias (abnormal movement and behaviours such as sleep talking and walking, bed wetting, and restlessness)

(Wengel et al., 2011)

Children with FASD have also been reported to have difficulties with sleep initiation/maintenance. They may also experience respiratory disturbance during sleep (Chen et al., 2012). Sleep problems are therefore an important area of functional impairment in FASD. Strategies to manage sleep problems have the potential to improve the lives of both parents and children.

Sleep helps regulate behaviour and improves health (Hanlon-Dearman, 2020). Sleep problems can be related to challenges with emotion, behaviour, cognitition, and school (Hanlon-Dearman et al., 2018). Lack of sleep may also cause anxiety (Hanlon-Dearman, 2020). When doing assessments on children for

challenging behaviours, clinicians may not ask about problems with sleep (Himmelreich et al., 2020). Caregivers may not know the impact that sleep challenges may have on children and may not discuss it (Himmelreich et al., 2020). Including a discussion and examination of sleep can help make sure the best supports are put in place for a child.

Studies have also found a positive correlation between sensory processing differences and the sleep patterns of young children affected by prenatal alcohol exposure (Fjeldsted & Hanlon-Dearman, 2009; Wengel et al., 2011). Fjeldsted & Hanlon-Dearman (2009), in their study with children aged 0 to 3 years with FASD, found a positive correlation between total daytime sleep and sensation-seeking; night wakefulness and sensation avoiding; as well as night wakefulness and oral sensory processing. In other words, children who slept less during the day were more active and sensation seeking (hyposensitive), possibly trying to achieve high neurological thresholds, while children who were awake more in the night avoided sensory stimuli (hypersensitive), because they likely have low sensory thresholds and try to avoid going above these thresholds (Fjeldsted & Hanlon-Dearman, 2009).

Fidgeting, rubbing/exploring objects, and chewing on objects are examples of sensory seeking behaviours that may be seen. Behaviours that indicate sensory avoidance can include being easily bothered by noise, lighting, and/or pajamas or blanket fabrics (Fjeldsted & Hanlon-Dearman, 2009). Sensory avoiders may appear withdrawn in the face of uncomfortable sensory experiences and may create rituals around familiar sensory experiences and become upset if these rituals are interrupted (Fjeldsted & Hanlon-Dearman, 2009).

<u>Strategies for Sleep Difficulties</u>

Addressing sleep difficulties in children with FASD can include a variety of approaches. Interventions usually involve a multi-disciplinary evaluation of the child's sleep (e.g., sleep questionnaires; sleep logs; descriptions of the sleep environment; and social, developmental and medical histories), as well as an Occupational Therapist's evaluation of sensory processing (Fjeldsted & Hanlon-Dearman, 2009; Hanlon-Dearman, Chen, & Olson, 2018). Interventions may be categorized as:

- cognitive strategies (e.g., sleep hygiene, social stories)
- sensory-based strategies
- medical strategies (e.g., medication)
- supportive environmental accommodations (e.g., altering the environment, reducing stimuli, manipulating sensory output, and self-regulation strategies)

(Fjeldsted & Hanlon-Dearman, 2009)

An integrated care plan involves looking at the effect of PAE on the physiological system; the child's neurodevelopmental strengths and weaknesses; and the past and current childcare environment (Hanlon-Dearman et al., 2018). Medical strategies can only be implemented by qualified professionals within the context of a multi-disciplinary team.

Sleep problems may be prevented and healthy sleep patterns cultivated through sleep-promoting practices otherwise known as “sleep hygiene” (Bathory & Tomopoulos, 2017). Sleep hygiene is a type of cognitive strategy that centres around establishing routines, in the form of consistent sleep schedules and pre-sleep routines (Bathory & Tomopoulos, 2017). Routines have the benefit of providing a sense of predictability and security and can help with activity transitions (Bathory & Tomopoulos, 2017).

Routines also have the added benefit of reducing caregiver-child conflict and improving family well-being (Sytsma et al, 2001). Bedtime routines serve as external cues that sleep is imminent, and help children to mentally prepare for sleep (Bathory & Tomopoulos, 2017). Regular bedtime routines improve the quality of sleep; in terms of time to fall asleep and frequency of night waking in infants and toddlers (Mindellet al., 2009). It is recommended that by about six months of age, parents should begin using a regular bedtime routine (Bathory & Tomopoulos, 2017).

Bedtime routines should be relatively brief (no more than 30 to 45 minutes) and involve the same type of relaxing activities before bedtime every day. This can include:

- warm bath
- bedtime story
- singing lullabies

(Galland & Mitchell, 2010)

The environment where the child sleeps should also be calm, quiet, dark, and warm, with no TV present (Dworak et al., 2007). Regular bedtimes, nap times, and corresponding wake times are also good practices of sleep hygiene and help to synchronize sleep and wake cycles with the circadian rhythm (Mindellet al., 1999). Other elements of good sleep hygiene include:

- waking the child appropriately at wake times
- encouraging vigorous physical activity during the day
- avoiding stimulating activity or foods (such as sugar and caffeine) near bedtime
- timing nap times so they are not too late in the afternoon
- avoiding media content, especially those with violent scenes before bedtime

(Bathory & Tomopoulos, 2017; Galland, Taylor, Elder, & Herbison, 2012; Garrison, Liekweg, & Christakis, 2011; Roehrs & Roth, 2008)

Sensory-based strategies can be used for sleep. They can include incorporating a “sensory diet” with approaches such as visual, auditory, oral, olfactory (smells/scents) and tactile and/or rhythmic movements (Fjeldsted & Hanlon-Dearman, 2009) into routine daily activities. This may include:

- the method of waking the child in the morning (e.g., lighting in the room, type of alarm or music)
- texture, temperature, and taste properties of breakfast
- regularly scheduled movement breaks
- physical activity during the day such as lifting and pushing
- vestibular input via linear swinging or rocking

(Fjeldsted & Hanlon-Dearman, 2009)

Part of the child's "sensory diet" can include a bedtime snack with desired calming sensory properties, such as sucking through a straw, or foods requiring "heavy work" for the mouth (for example, chewing bagels) (Fjeldsted & Hanlon-Dearman, 2009). A pictorial representation of the "sensory diet" may be helpful for the child and strategies should be used consistently for two to four weeks before determining their effectiveness (Fjeldsted & Hanlon-Dearman, 2009).

Visual approaches for the sleep environment include a bedroom that is visually uncluttered and calm, with dark/low lighting and limited distractions (Fjeldsted & Hanlon-Dearman, 2009). Examples include the use of a slow rhythmically moving object like a fish tank to give a calming effect, room darkening blinds to maintain low lighting, or having the child sleep in a tent to limit visual distractions (Fjeldsted & Hanlon-Dearman, 2009). For auditory strategies, placing carpet in the room to absorb noise can be useful. "White noise" (e.g., from a fan) can be calming and help to drown out other noises (Fjeldsted & Hanlon-Dearman, 2009). Relaxing music, or music with a strong beat, has also been reported to help aid students to fall asleep in a classroom (Fjeldsted & Hanlon-Dearman, 2009).

There are tactile-focused methods which support sleep, such as:

- softening new pyjamas by repeated washings
- removing tags from clothing
- providing deep pressure or a calming massage
- using hand fidgets such as a stress ball or blankets with preferred fabric pulls
- using sleeping bags or "nesting" with stuffed animals

(Fjeldsted & Hanlon-Dearman, 2009)

Slow rhythmical linear rocking, such as in a rocking chair, can be calming before bed. Fast movements in various directions (e.g., running or spinning) are not recommended before bedtime since they can cause overstimulation (Fjeldsted & Hanlon-Dearman, 2009). Scents in the home (e.g., laundry soap, fabric softener, toothpaste, body soap, or lotions) can be overwhelming for children with FASD. Choosing scents that are calming for the child (e.g., vanilla, banana, or lavender) may be helpful (Fjeldsted & Hanlon-Dearman, 2009).

Insecure Attachment

Secure attachment is important for a child's healthy development. Attachment behaviour is a behaviour that prompts another individual who is perceived as being better able to cope with the world, to get or keep close to the individual expressing the behaviour (e.g., crying, reaching, smiling, snuggling) (Bowlby, 1982). This development starts during infancy and impacts long-term functioning. It is based on a child's early caregiving experience (Bowlby, 1982). Infants with secure attachment have shown greater resiliency (having the ability to respond flexibly, persistently, and resourcefully between the ages of 4 to 5 years) (Arend et al., 1979). Teachers have also rated preschoolers with a secure attachment as being more social, having more friends, and showing fewer negative emotion (Sroufe, 1983 as cited in O'Connor et al., 2002). On the other hand, infants with insecure attachment have been associated with

the development of anxiety, internalizing and externalizing behaviours, as well as conduct disorders in early childhood (Bates et al., 1985; Speltzet al., 1999).

The relationship between prenatal alcohol exposure and the early caregiving environment is complex. Bio-behavioural research has shown that infants with moderate to heavy PAE are more vulnerable to stress and experience a higher risk of regulatory problems (Jirikowic et al., 2016). When infants have a weakened ability to cope with stress and control negative emotion and mood, it can contribute to problematic mother-infant interactions, and later socioemotional problems as the child matures (O'Connor & Paley, 2009). It has been found that women who drank more heavily during pregnancy had infants with higher levels of negative affect in mother-infant interactions and these mothers responded less sensitively to their infants (O'Connor & Paley, 2009). Later, these infants had higher levels of insecure attachment and eventually higher levels of depression.

One program, Breaking the Cycle, looked at their model of supporting biological parents before birth and after. They noted that mothers were more emotionally available and better functioning parents the longer they stayed with Breaking the Cycle (Motz et al., 2020). The children whose mothers had stronger parental skills and were more emotionally available had fewer problem behaviours (Motz et al., 2020).

Other studies have reported an increased incidence of insecure attachment among infants and children with prenatal alcohol exposure (PAE) (O'Connor et al., 1987; O'Connor et al., 2002). One showed a high prevalence (80%) of insecure attachment in a sample of four- and five-year-olds (O'Connor et al., 2002). Children with FASD often have complex developmental and emotional-behavioural needs that stress the child-caregiver relationship and puts them at greater risk for attachment-related challenges (O'Connor et al., 1987; O'Connor et al., 2002). When mothers of such temperamentally vulnerable infants were able to provide a supportive presence, the child developed a better ability to cope with stress and frustration and better attachment security (O'Connor et al., 2002).

Child welfare involvement also increases the risk of developing insecure or disorganized attachments with primary caregivers. This can happen because of multiple or disrupted placements (Hanlon-Dearman et al., 2015; Lange et al., 2013). The quality of the mother-child relationship affects the cumulative risk and FASD-related neurobehavioural outcomes for infants and young children (Motz et al., 2011). Stable caregiving environments and long-term protective relationships have been shown to improve positive social and emotional development (Koponen et al., 2009). This is important for children with FASD. Research suggests that interventions should support the caregiver's reflective capacity (looking at their own and their children's mental states). Caregivers and children should be targeted at the same time (Pillhofer et al., 2015; Suess et al., 2016).

Cumulative Risk

The sum of risk factors experienced (e.g., prenatal alcohol exposure, poverty, domestic violence, maternal mental health issues)

Strategies for Preventing Insecure Attachment /Promoting Secure Attachment

If the mother can provide a supportive presence or secure base, the child can deal with frustration and stress and develop secure attachment relationships (O'Connor et al., 2002). Most strategies to improve insecure attachment are structured interventions or program-based. There is a focus on improving parental sensitivity (developing skills that enable parents to understand their infant's signals and adjust to their cues consistently, especially when the infant is distressed) more than directly on improving attachment security (Klein Velderman et al., 2006; Wright et al., 2017). It has been hypothesized that past attachment experiences of parents (with their own family of origin) may impact their ability to respond sensitively to the attachment signals of their child, especially when their own inner working model of attachment has remained insecure (Klein Velderman et al., 2006). Enhancing both parental sensitivity and parental attachment may lead to stronger and more persistent changes in the child's attachment security (Klein Velderman et al., 2006).

There are interventions that have improved parental sensitivity and improved attachment security in young children (Anisfeldet al., 1990; Bakermans-Kranenburg, Van IJzendoorn, & Juffer, 2003; Heinicke et al., 1999). Anisfeld et al., (1990) found a fundamental association between physical contact (through carrying an infant in a soft baby carrier) and the attachment security between mother and baby. Interventions focused on sensitivity and/or attachment were most effective if the intervention sessions were aimed at sensitive parenting behaviour and included only a moderate number of sessions (Bakermans-Kranenburg et al., 2003). Video feedback is also commonly used in interventions with a primary focus on maternal sensitivity. It lets the parent review the infant's cues and needs, and reflect on their responses to them (Wright et al., 2017).

One very small study used a modified version of Circle of Security [COS] and home-based visits. The goal was to build attachment between caregivers and their children with FASD between the ages of two and five (Hanlon-Dearman et al., 2017). The results were positive and had a positive impact on children's behaviour. The small study size is a limitation but may inform other programs (Hanlon-Dearman et al., 2017).

Feeding Difficulties

PAE may negatively impact food and eating behaviours, as well as nutrition (Wert et al., 2013). Infants with FASD are also at risk of a condition known as "Failure to Thrive" because of gastrointestinal disorders and conditions that reduce feeding behaviours and require specialized nutritional support (Sujay et al., 2012; Vasiliauskas et al., 1997). One study showed recurring feeding/dietary issues in children with FASD including:

- picky eating/poor appetite
- constant snacking
- not physically feeling full

(Werts et al., 2013)

There were also a few reports of children refusing certain textures and having chewing difficulties. Results from the same study also suggest that children with PAE may be at risk for nutritional deficiencies, because of:

- inappropriate food preferences
- disordered eating patterns
- medication use
- stressful dynamics surrounding food preparation and mealtimes

(Werts et al., 2013)

As earlier discussed, children with FASD often struggle with hypersensitivity and hyposensitivity to sensory perceptions, including taste, smell, sight, hearing, and touch. Eating involves all these five senses which can make it unpleasant for individuals with FASD (Badry & Hickey, 2018). For instance, the crunchiness, brightness, or the aroma of a type of food may be disturbing for a hypersensitive individual. Being "picky" about foods may be a way of protecting themselves from the unpleasant feeling associated with the hypersensitivity (Badry & Hickey, 2018). On the other hand, for hyposensitive individuals, eating can be just as challenging as food may not smell appetizing, may taste bland, and provide no tactile stimulation (Badry & Hickey, 2018).

Not all feeding issues in children with FASD are sensory in nature. Other factors that can contribute to disordered eating include:

- muscle weakness
- lack of coordination
- distraction

(Badry & Hickey, 2018)

Muscle weakness, such as hypotonia (low muscle tone) can cause the child to become easily tired when chewing or bottle feeding (in the case of infants) or the child may find it difficult to sit for the entire meal. For example, children with FASD may struggle to swallow properly due to an inability to coordinate all the muscles involved in swallowing (Badry & Hickey, 2018). A lack of coordination may make the child frustrated with eating utensils and they appear to be messy eaters as food spills during mealtimes. A lack of coordination can also cause meal times to be longer. If meals need to be eaten in a limited amount of time, the child may be unable to finish her food. Lastly, mealtimes are often a social occasion. This can be a major distraction for a child with FASD (Badry & Hickey, 2018).

<u>Strategies for Feeding Difficulties</u>

The following are some useful approaches to handle feeding difficulties and meal times:

- Allow plenty of time for the child to eat.
- Avoid spicy foods for young children if they react to strong flavours.
- Think about the temperature and texture of foods based on the sensitivity of the child.
- Establish a firm routine during meal times (e.g., require that the child take at least one bite of everything).

- Have reasonable expectations of portion size.
- If late-night eating is a problem, establish rules about eating at the table only and a light snack just before bed.
- If using forks and knives is a problem, allow the use of fingers or a spoon. This allows the child to also experience new food freely.
- Try keeping the same routines at every meal (e.g., use the same dishes at every meal); serve meals at the same time daily; give the child a specific seat at the table; and consider having the same meals on the same days (this helps the child to "know" the day of the week).
- Avoid eating out during peak times; instead, look for quiet restaurants with low light and minimal noise.
- Introduce one kind of table manner at a time. Integrate a new "manner" only when the previous one has been successfully learned.
- For picky eaters, keep offering new food and try pairing new food with really loved food.
- Get the child involved in food preparation, especially for new foods that they may be reluctant to try. This exposes the child to new food and gives them a sense of accomplishment, encouraging them to try the dish once it is done.
- Reduce distractions at mealtimes by avoiding TV, radio, and too much conversation.

(Badry & Hickey, 2018; Society of Special Needs Adoptive Parents (SNAP), 1999)

Specific ideas for infants include:

- reducing external stimulation (e.g., feeding the baby in a darkened, quiet room will help him relax and focus on sucking)
- wrapping baby in a blanket which may help to calm him during feeding
- pressing baby's chin upward in a gentle, rhythmic pattern
- stroking baby's lips and gums gently before breastfeeding or bottle-feeding
- trying different nipples till one that works well is identified (if bottle-feeding)

(Society of Special Needs Adoptive Parents (SNAP), 1999)

The Role of Occupational Therapists

Occupational therapists (OT) are often involved in the diagnosis/assessment and intervention of FASD (Cook et al., 2015; Jirikowic et al., 2008). Occupational therapy intervention is important in improving functioning and independent living across the life of an individual with FASD (Jirikowic et al., 2008). Occupational therapy can help children with FASD develop their fine and gross motor skills, cognitive skills, social skills, as well as independent living skills. This can build success in their daily lives. OTs also provide strategies that help with sensory processing issues. Some examples of strategies and interventions used by OTs include the following (Barnett & Hannan, 2019):

- Motor skills: fine motor and motor planning skill development, handwriting programs, use of alternative technology
- Self-care/daily living/organization: task analysis, co-op approach (cognitive orientation to daily occupational performance), and skills training
- Play skills: play therapy, motor skill development, learn to play, and DIRFloortime®

- Self-esteem/social skills: strength-based approach and social skills group
- Sensory processing/behaviour regulation/arousal/attention difficulties: use of visual schedules, sensory activity schedule, and cognitive strategies

Sensory-based interventions also include "The Alert Program®" and "Zones of Regulation". Generally, sensory intervention by OT's involves skilled application of somatosensory input (movement, tactile, and proprioceptive) to improve children's functional and adaptive skills (Jirikowic, 2007).

Other Promising Strategies

Evidence shows that building caregiver and child strengths are promising ways to improve outcomes in children with FASD.

Focus on Caregiver Strengths

Certain caregiver factors have been identified as important in increasing positive outcomes in children with FASD. These include:

- knowledge and education about FASD
- locating and maintaining professional and personal supports (such as respite care, school, family, and friends)
- having a stable and positive home environment (including maintaining structure, routine and consistency; strong caregiver communication skills; and positive caregiver attitudes)

(Kapasi & Brown, 2017)

Research has also shown that families of children with intellectual and developmental disabilities often do better with professional and informal supports (Bailey, 2007). Appropriate training, support, and assistance with practicing can help parents improve interaction with their children. This can enhance language and cognitive development, decrease depressive symptoms and psychological issues, and improve the feeling of self-efficacy amongst other family outcomes (Bailey, 2007).

Recognize and Build Child Strengths

As mentioned earlier, it is important to remember children's strenths and build on them. Parents can be very useful in identifying strengths in their children.

Recognizing and encouraging these strengths by caregivers has been recognized as important (Badry & Hickey, 2018; Petrenko et al., 2019). It has been put forward that other professionals are oftentimes focused on what is not working (Badry & Hickey, 2018). Drawing attention to what is working or what strengths the child has can ensure those strengths are not lost (SNAP, 1999), help build confidence in the child (St. Michael's Fetal Alcohol Spectrum Diagnostic Clinic, n.d.), and possibly lead to some creative solutions (Badry & Hickey, 2018).

General Caregiver Strategies for Supporting Children with FASD

Generally, many different approaches have been found to be promising in supporting children with FASD. This list is not exhaustive but includes the following:

- A high level of monitoring, vigilance, and supervision at all developmental periods[1,2]
- Implementing and maintaining structure and routine[1,2,3,4] such as:
  - breaking down daily activities into specific steps
  - doing everything in the same way and in the same order every day
  - using calendars to list events, e.g., in the kitchen and bedroom
  - posting key family rules in simple words
  - preparing the child for school the night before
  - ensuring consistency with language, rewards, and routines[1]
  - providing frequent prompts and reminders (including non-verbal, sensory, and visual cues to support memory and executive functioning)[1,2]
- Supporting the child's strengths and interests[1,2]
- Adapting and tailoring parenting strategies that support the unique needs of the child[2,3,5]
- Staying patient and understanding, maintaining flexibility, as well as providing a loving environment[3]
- Ensuring effective communication at all times, using simple and short directions, and being prepared to repeat instructions and rules[1,4]
- Teaching the same skills in different environments to allow for transferring skills[3]
- For major transitions, using pictures/photographs to prepare the child for such events (e.g., moving to a new home, going to the dentist/doctor, going to the hospital, or going to a new school[4]
- For infants and toddlers, moderate/light pressure massages have been shown to lead to more organized behaviour in the child as well as decrease stress behaviour and movement[6]
- Recreational activities which help to stimulate general development, skills training, and opportunities for socializing with peers[6]

([1]Carpenter, 2011; [2]Petrenko et al., 2019; [3]Kapasi & Brown, 2017; [4]SNAP, 1999; [5]Domeij et al., 2018; [6]Olson and Montague, 2011).

Non-traditional approaches include (Kapasi & Brown, 2017):

- the use of Aboriginal or cultural methods (such as spiritual strengths and traditional medicines)
- listening to music
- incorporating a service dog into the home as service dogs have been shown to help individuals with FASD with issues like sensory overload; safety, especially with impulsive behaviour; calming, empathy, social and communication skills; as well as improving independence (4 Paws for Ability, 2019).

Conclusion

Overall, FASD is a broad and complex issue with implications for individuals, caregivers, families, communities, and society. While it is important to recognize these issues, it is also important to keep in mind that children impacted by prenatal alcohol exposure have many positive characteristics.

The impacts of PAE can be seen from as early as the period following birth, through infancy and childhood, and up into adulthood. Despite the knowledge that early diagnosis before the age of six is an important protective factor for the development of adverse outcomes, research shows that the average age of diagnosis is usually later than this (sometimes as late as 9.5 years). In particular, gross and fine motor function challenges; cognitive impacts; attention difficulties; irritability; hyperactivity and impulsivity; insecure attachment; social skills challenges; speech and language problems; sleep difficulties; sensory processing problems; and feeding difficulties appear to be prevalent during the period of zero to six years.

These difficulties ultimately impact different aspects of the child's development, everyday life, schooling, and social relationships, making early intervention necessary. Caregivers play an important role in supporting children with FASD and improving their outcomes by using several promising strategies as detailed in this review. However, more research is required in some domains such as executive and motor function; speech, language, and communication; attention and memory; visual-spatial function; and functional/adaptive skills where there is currently a lack of promising caregiver strategies.

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