

Towards Healthy Outcomes

A Framework for Integrated Community Intervention

INTERVENTION NETWORK ACTION TEAM OF
THE CANADA FASD RESEARCH NETWORK



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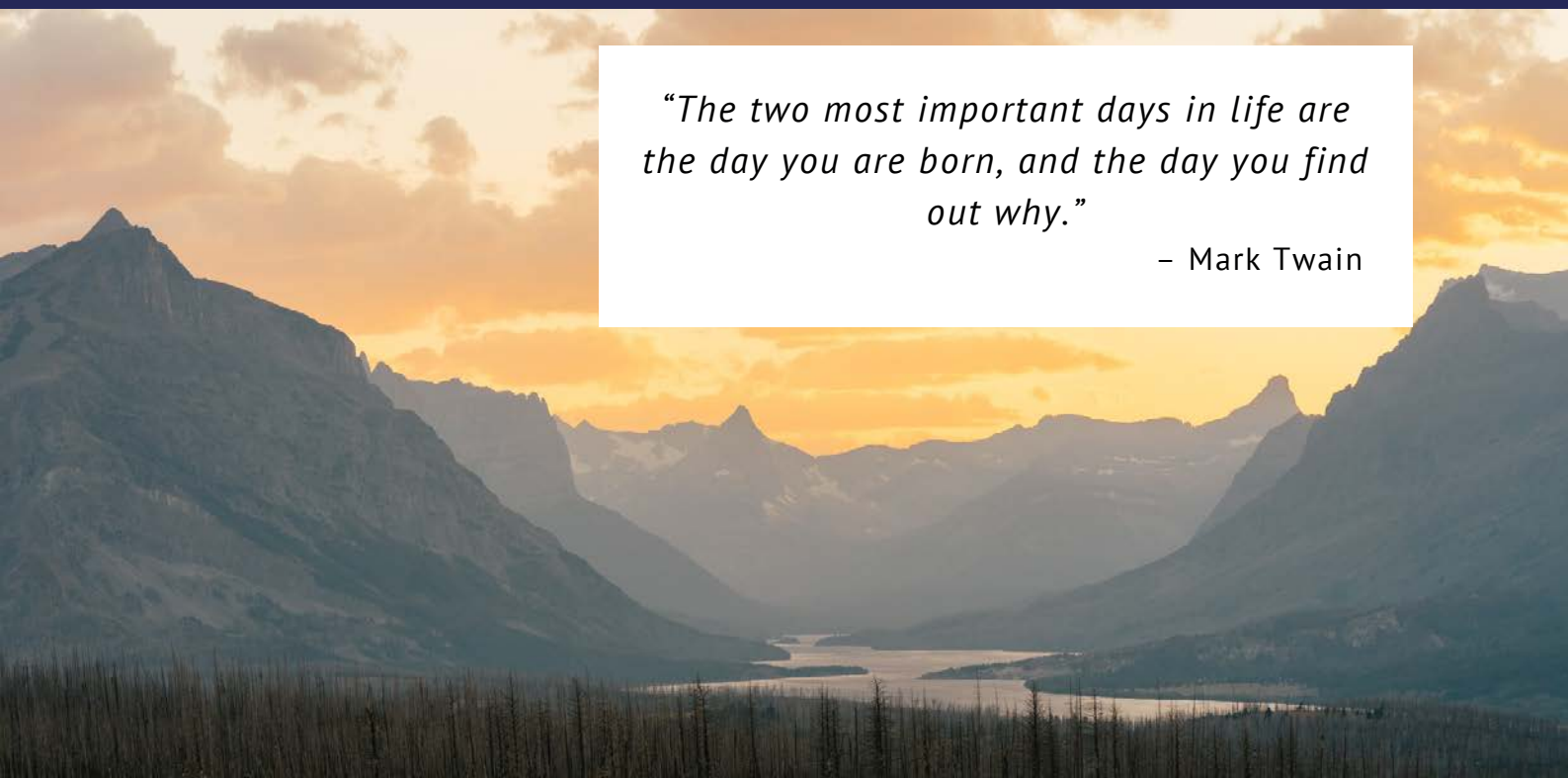
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TOWARDS HEALTHY OUTCOMES 2.0



“The two most important days in life are the day you are born, and the day you find out why.”

– Mark Twain

Meaning, purpose, belonging. These are important to the human experience and underlie many of the goals embedded in human activity. Researchers will tell you that achieving these goals contributes to a wide range of desired developmental outcomes across the lifespan, yet this information is unsurprising – it is intuitive for most of us. We recognize in our experiences that it is not enough to ‘get by’ in life; rather, we must feel we have something to offer. We need to feel we have some ***purpose***, that we ***belong*** somewhere, and that we can ***meaningfully contribute*** to society.

From infancy through adulthood, we are first raised and then, in some fashion, contribute to raising others to find their place and experience success that is meaningful to them. However, for some, finding this pathway, and meeting developmental expectations held by our societal systems, such as within schooling or employment settings can be very challenging. **Particularly for those with disabilities, the process of pursuing desired outcomes may not align with expectations wherein a range of “normal” is externally defined and planned for – and diverse strengths and opportunities are missed.** Susan Hampshire stated:

“It is a lonely existence to be a child with a disability which no one can see or understand, you exasperate your teachers, you disappoint your parents, and worst of all, you know that you are not... stupid.”

Consequently, systems of support are often focused on identifying, and then accommodating or mitigating deficits and reducing risks that may arise. In doing so, we have shifted focus away from the individual and their growth towards the systemic obstacles to be navigated and problems to be addressed; for many, this may contribute to anxiety and uncertainty about the future. Gone are thoughts of meaning, purpose, and belonging - and other goals to work towards.

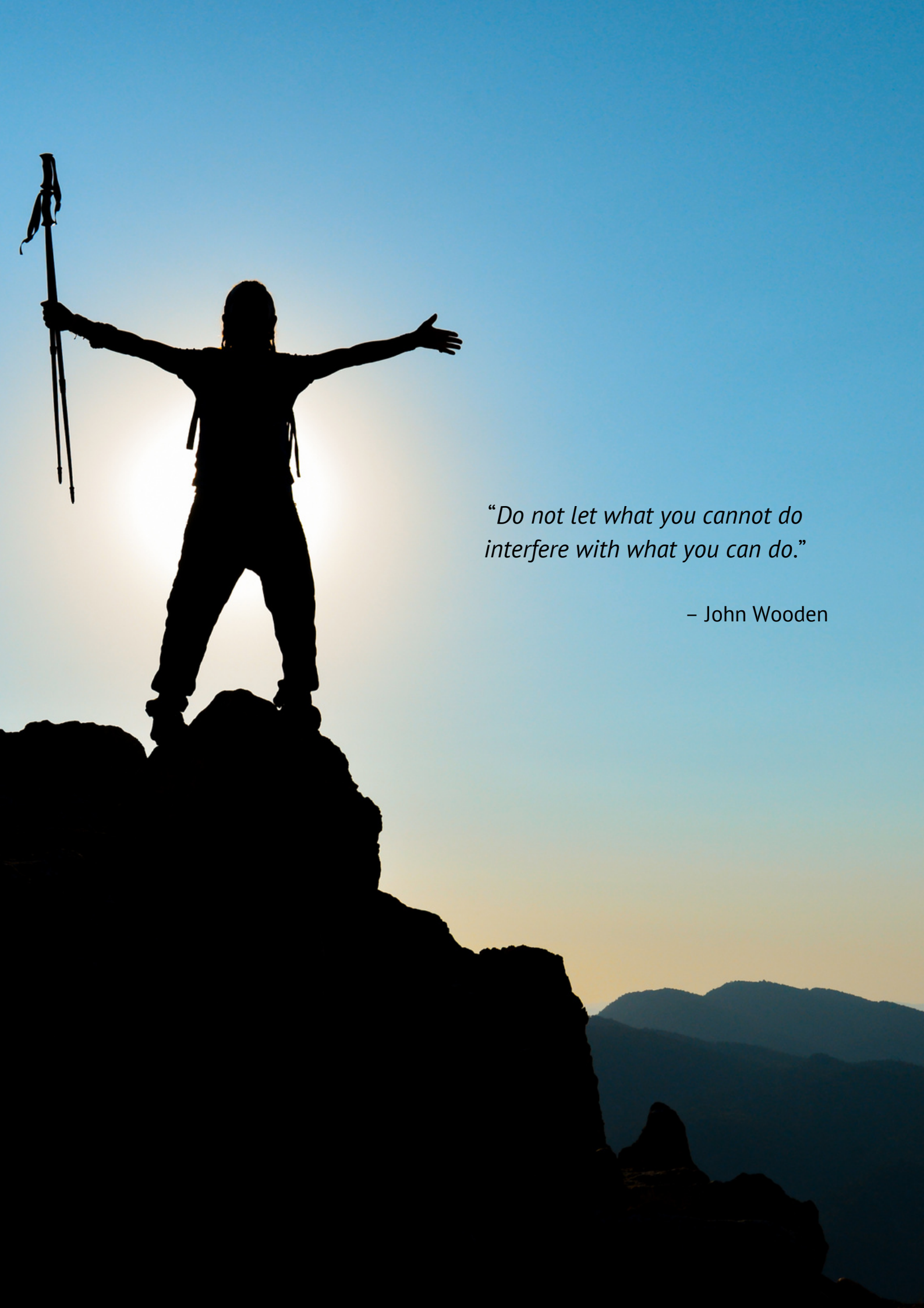
This response may be particularly pronounced with people who have unique and diverse needs and strengths, such as those with fetal alcohol spectrum disorder (FASD).

Our hope for this framework is to continue highlighting ways we might walk with individuals with FASD in pursuit of healthy outcomes, at individual, family, community, and systems levels.

In this framework, we choose to address the brain-based challenges and needs identified for individuals with FASD within a goal-oriented and strengths-based framework. Informed by the wisdom of caregivers and those with living experience, we hope this framework supports a balanced understanding of each individual's needs and strengths with particular consideration for ways to support healthy outcomes. In adopting this perspective, we emphasize the value that each individual with FASD brings to their own story and all of our communities and highlight our commitment to finding support and intervention pathways that promote movement towards desired outcomes.

This perspective provides us with the backbone of the THO framework. Additional details regarding the underlying thinking that drives THO are provided in the 'beliefs' and 'philosophies' sections. We feel that, much like this framework, our actions are grounded in our beliefs, so we begin in this reflective space.





*“Do not let what you cannot do
interfere with what you can do.”*

– John Wooden

Towards Healthy Outcomes Framework



Towards Healthy Outcomes (THO) is a framework. It provides a structure that can guide consistent and integrated practice, facilitate shared understanding and communication, and direct policy and inform perceptions. And challenge stigma. By pulling resources and ideas together, in a structured and intentional way, we provide communities with a dynamic resource that will facilitate integrated and collaborative planning forward.

This framework provides opportunities to **deepen knowledge** through provision evidence based developmental, FASD, and intervention content. Throughout, we encourage application of this knowledge to **challenge bias** through open dialogue, and to continue to **monitor impacts and outcomes** for ongoing adaptation as needed.

By increasing our understanding, reflecting, and monitoring impacts, as individuals and communities, we engage in shared practice that can support progress towards healthy outcomes.

New to THO

THO was first introduced in 2019. Thanks to an incredible community response and continuing feedback, we have been able to produce THO 2.0. Although many elements of the framework remain the same, readers will note some changes from the original version. In response to community feedback, we have:

- **Reduced the framework** to include ten domains. The Attachment and Family Cohesion domains from the original THO were integrated to produce a singular *Attachment and Relationships* domain; Adaptive Functioning and Community Engagement have been combined to make *Interdependence*.
- **Modified the names** of all domains to reflect our strengths-based, goal-oriented perspective better.
- **Actioned research** by helping readers consider “what can I take and apply from this?”
- **Infused themes** of ‘across the lifespan’ and essential contributions from culture, community, and relationships.
- **Highlighted the voices** of those with living experience.
- **Noted action items** and policy implications throughout.



We have also organized content in a more systematic way. In each domain there are now three sections:

1. Learning

About basic developmental domains and contributions to lifelong functioning.

2. Understanding

How development may be uniquely impacted for individuals with FASD, thereby calling for adaptation to expectations and support, as well as goal setting to facilitate growth in the *FASD-Informed* section. Researchers, community members, and families have reminded us that meaningful outcomes arise from meaningful understanding. Taking this perspective steers us towards the question, “What do I know?” instead of “What do I do?”.

This highlights a shift in our approach to goal pursuit – it is neither “can’t” nor “won’t,” but rather “how?” **How do we support each individual towards healthy outcomes?**

3. Enacting

FASD-informed approaches to intervention and support based on current FASD resources and research evidence in the *Moving Together* section. Throughout we continue to use the language of “intervention approaches” to capture the targeted and supported aspects of intervention. Links to FASD-informed tools can also be used to inform ongoing support in each domain across the lifespan.

Towards Healthy Outcomes for Individuals with FASD



Core Beliefs

Our beliefs drive our actions. Thus, THO remains grounded in our core beliefs and values:

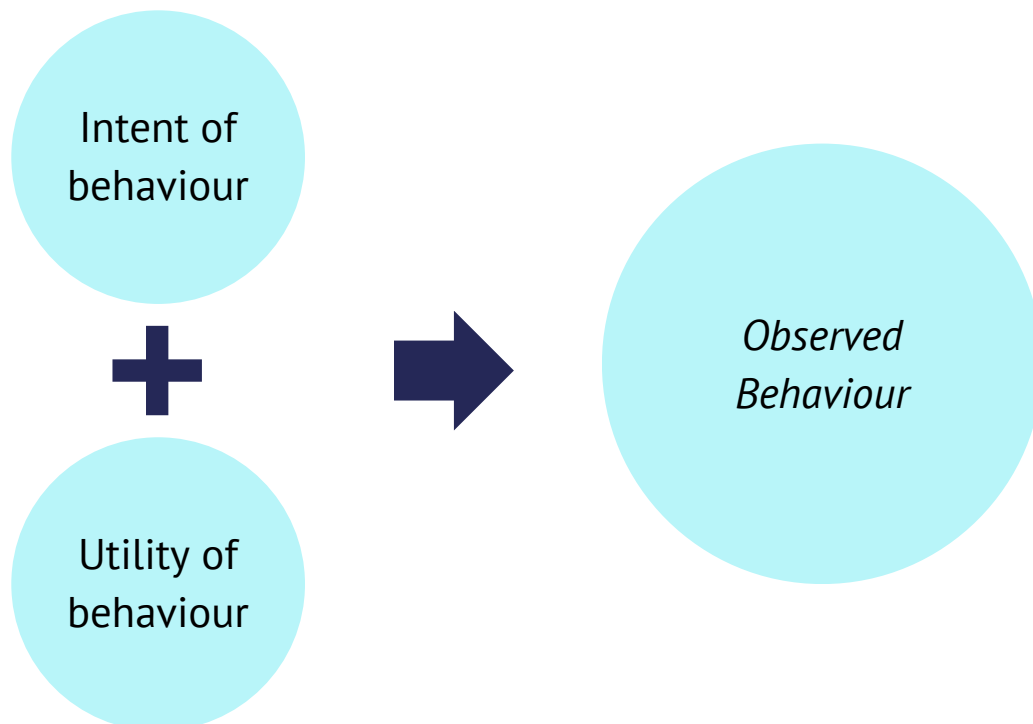
Individuals with FASD are capable of growth and can contribute meaningfully to their communities - and are doing so.

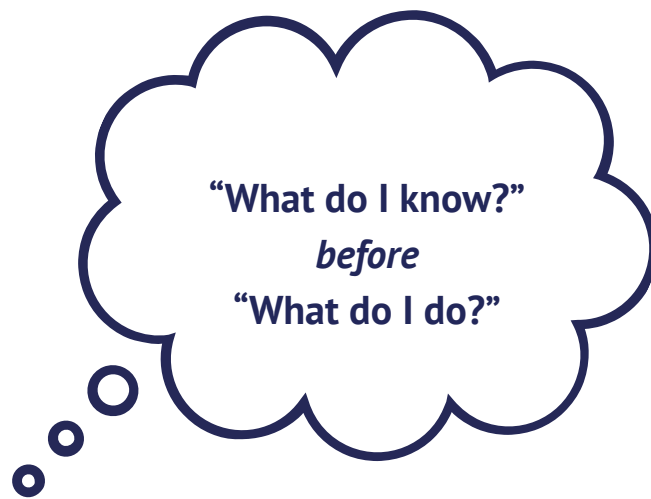
This is supported by research as well as our direct learnings from those with living experience. We are better for these relationships and contributions to our communities. This perspective promotes a *growth mindset*, which is the belief that, like all people, the abilities of individuals with FASD are not fixed, and growth is possible with effort and appropriate support. This also reflects the value we hold for our friends, colleagues, community, and family members with FASD and drives our pursuit of healthy outcomes for all community members.

Individuals with FASD have both strengths and needs.

There is no shame in difficulties; they must be acknowledged – they are part of who we are – all of us. However, they are not all of who we are. We must invest in inquiry and understanding of strength and possibility with the same energy that we explore difficulty and risk. A balanced perspective reveals the whole person. Practically, we extend this to challenge our perceptions and assumptions when working with individuals with FASD as we support their goal pursuit. To this end, we offer that *all behaviour is functional*. We all interpret and respond to the world in unique ways. For individuals with FASD, interpretation and response may reflect unique patterns of brain-based functioning. By working together, we may increase our understanding of the goals met through behaviours and consequently identify alternative approaches to goal pursuit and developmental support that may align with more and longer-term desired outcomes.

Figure 1. ***Underlying Causes of Observed Behaviour***





The voice of living experience matters.

Success is co-created as we walk with, not for, individuals with FASD. Calls for “Nothing About Us Without Us” (Reid et al., 2022) highlight the need for people with living experience to have their voices not only heard but included in initiatives that directly impact them. Honouring the expertise of people with living experience, including caregivers, family members, and individuals with FASD, enables supportive others to engage in intervention and other work that is likely more meaningful for those impacted. Individuals and families have the right to participate in decisions about their current situations and their futures.

Our relationships and connections influence developmental outcomes.

We do not exist in isolation, and our experiences, supports, and actions are all informed by the environments and communities in which we reside. Relationships are central to daily life, from meeting basic needs to achieving goals. Identifying and working within a person’s relationships with others when working towards healthy outcomes is critical.

We need shared understanding.

As our understanding grows, we better position ourselves for more appropriate and empowered intervention approaches. We emphasize that understanding must be more than a word or a sentiment and, instead, must be derived from collaborative and careful inquiry. Shared understanding may refer to knowing why an individual may be struggling, how others have attained success, and/or the challenges imposed by systems of support. Failure to establish shared understanding may lead to misinterpretation, frustration, and disengagement. Conversely, shared understanding creates space for creative and responsive support, intervention, and planning tailored to each individual’s unique strengths and needs.



Philosophical Model

Congruent with these beliefs, we identify three core tenets to be considered by all services, supports, and developmental opportunities employed in pursuit of healthy outcomes: 1) a developmental lifespan perspective is necessary at all ages and stages, 2) interactive systems and environments have additive and ongoing influences on the individual, and 3) our direction needs to remain goal-oriented – focused on desired outcomes, and embodying an empowered and strengths-based approach. These core, interactive, tenets guide the design and implementation of the model.

A developmental lifespan perspective.

Individuals grow and change over time, both in terms of their capacities (strengths and difficulties) and goals. In any given moment, we exist within our present developmental capacities while we are influenced by our past and looking into our future. In this same way, intervention approaches need to reflect each individual's unique developmental capacities, with knowledge of how their growth has been and continues to be influenced by experiences and interactions with systems and people. This shapes the direction of goals, actions, and experiences of meaning and belonging throughout our lifespan.

Strengths-based and empowered.

By engaging and walking alongside individuals with FASD, families, and support systems, we may build a relevant, balanced, and informed understanding in which acknowledging strengths and autonomy remain central. For every person, strengths and weaknesses may be identified, supported, and mitigated within each domain of this framework. A strengths-based and empowered approach vests power in individuals with FASD and their families and casts service providers as partners.

Interactive systems.

Combining individual strength and engagement with active involvement of support systems creates conditions for success. We must all interact fluidly and flexibly in response to individual needs at different times throughout the lifespan. Children, families, and adults frequently receive support from many sources and collaboration, communication, and cooperation are essential to best support individuals with FASD. This requires intentional collaboration and responsivity between service providers and individuals with FASD and their families. As you will see as you continue reading, the woven layers of colours in the model represent the cumulative impact and influence the domains have on each other.

"I am neither an optimist nor pessimist, but a possibilist."

- Max Lerner



*“If you surround yourself with love and
the right people, anything is possible.”*

– Adam Green




How can you use the THO 2.0 framework?

A framework provides a shared language, a way of highlighting and organizing goals, and a structured approach to intervention among community members, people with living experience, and support systems. When we share a framework, synergy and purpose are more easily aligned – and we can move together towards healthy outcomes.


When actioned, THO 2.0 establishes a framework that promotes consistent, goal-oriented intervention planning across the lifespan. Thank you to **Rob More, Jeff Noble and the Caregiver Club, Annette Cormier, and Robbie Seale & Elizabeth Presley**, who have kindly shared their experiences enacting THO:

Guiding Integrated Policy Development




THO was used as a guide for an environmental scan of existing services and supports available in the Lanark and Leeds-Greenville regions of Ontario, Canada. Conducted by the Open Doors and Rural FASD Support Network in May 2022, organizers contacted local FASD service providers to gather information regarding the availability of local FASD-informed resources and supports. Findings highlighted supports and resources available within their local region in accordance with the 12 domains highlighted by the original THO framework. The participating organizations reported using THO to support individuals with FASD and their caregivers in navigating complex systems. More information can be found on their webpage: <https://ruralfasd.ca/about-us/>

Guiding Intervention Planning




THO is in use by an international, virtual community of caregivers. The caregivers meet twice weekly to discuss the realities of supporting individuals with FASD and to discuss educational modules based on THO. The modules facilitate access to resources and literature, provide strategies for supporting individuals with FASD, and communicate information to caregivers regarding the importance of maintaining their own wellbeing. The use of THO to structure these modules has helped caregivers to better understand FASD and the impact that brain-based differences can have across multiple domains of healthy functioning. Caregivers have also learned strengths-based strategies that are developmentally appropriate for use when supporting individuals with FASD.

Establishing Continuity of Care



The THO framework was integrated as part of a provincial resource guide to produce a *FASD Community Guide, Resources and Services Across the Lifespan* in New Brunswick. The document continues to evolve and is intended to help guide professionals working with individuals with FASD. Those who receive the document include healthcare, mental health, education, social development, and Justice and Public Safety workers.



Also, in New Brunswick, Community Coordinators and Aboriginal Liaisons utilize this resource guide, including the domains and pathways specific to THO, as they help families navigate complex systems. Using THO in this way has successfully created an understanding of the importance of a strong roadmap or pathway to wellness.

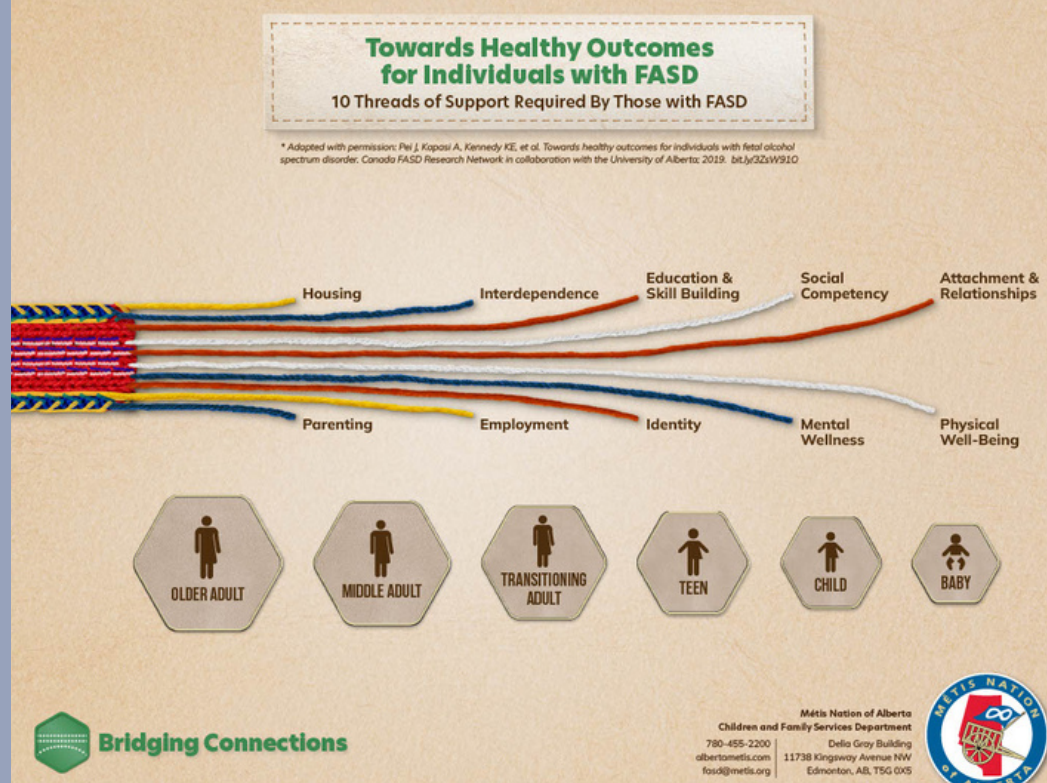
Bridging Futures

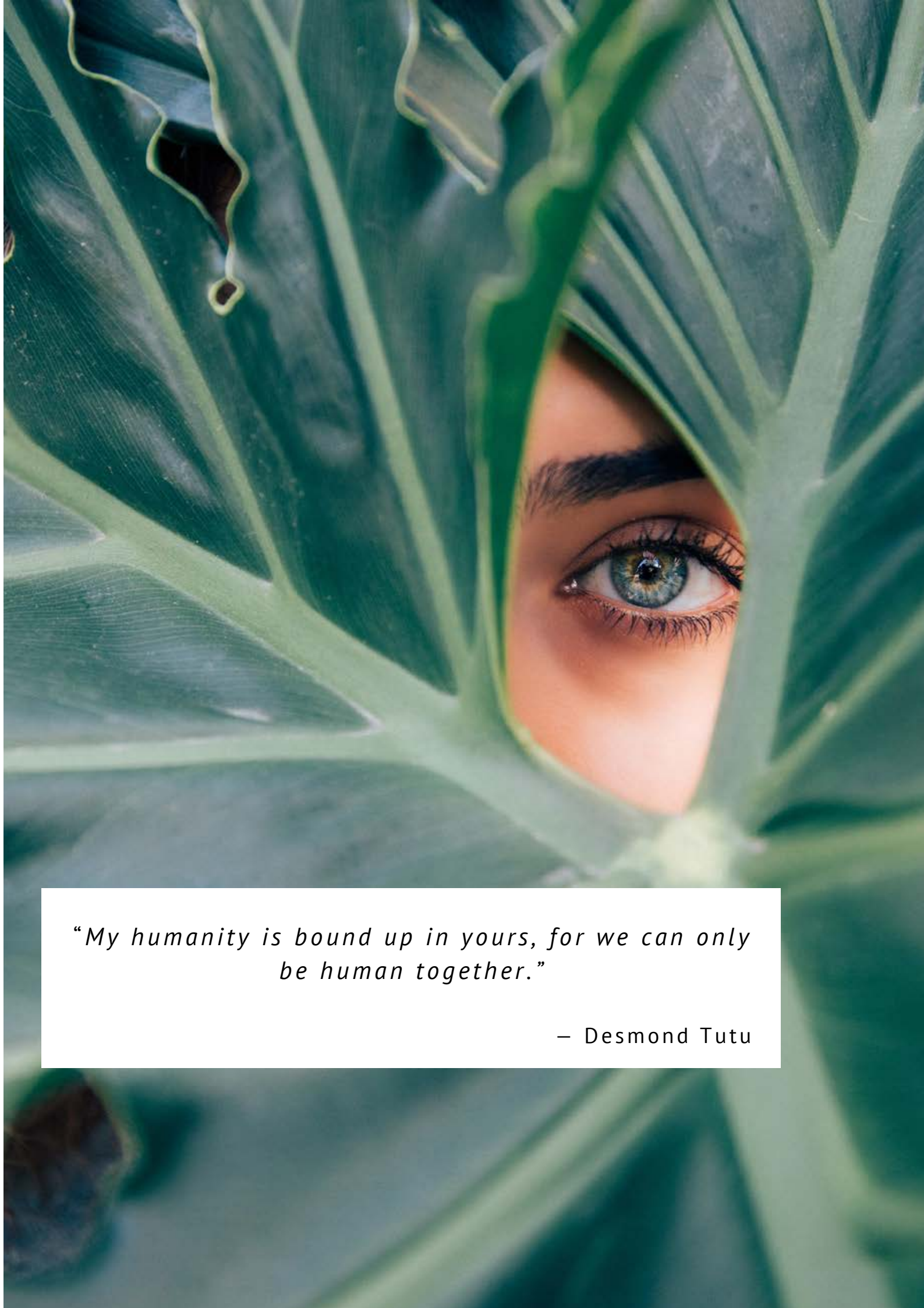
The Otipemisiwak Metis Government's Children and Family Services Department has developed a brand-new resource based on THO, called the *FASD Bridging Futures Guidebook*. This guidebook will assist parents/caregivers and Metis youth to create a transition plan so they can confidently cross the bridge from adolescence to adulthood with the supports in place they need. This beautiful *10 Threads of Support Graphic* (see Figure 1) was specifically designed for this project. The team arrived at this final design after consultation with Dr. Pei and a young adult with FASD.

The Métis sash is one of the most recognizable symbols of Métis culture and identity. The sash was hand-woven, made in various lengths and historically was worn as an accessory and tool with a variety of uses—for example, a belt, rope, sling, scarf, washcloth, etc. The Métis Sash continues to be a symbol of beauty, utility, strength, resilience, and unity for Métis people. This image was chosen to illustrate the diverse and interconnected threads that contribute to the fabric of stability and well-being for Métis people with FASD. Within the sash, ten crucial threads are identified as representing the support required for individuals with FASD for the optimization of improved outcomes. The thread that binds all these together is healthy, strong relationships with adults who see the individual with FASD for who they are, not just their disability.

The FASD Building Futures Guidebook - Ten Threads of Support graphic will also serve as a valuable tool for community, service providers, family, friends, and individuals with FASD in identifying the supports required to improve outcomes. This graphic will raise awareness of FASD in our communities and the types of supports required for optimal wellness for Métis people with FASD. By embracing these ten threads of support, this team aspires to bridge the gaps in understanding, policy, and service delivery for Métis people with FASD, offering a path toward enhanced well-being, fulfillment, and meaningful connections in a world that embraces diversity and inclusivity.

Figure 1 - The Ten Threads of Support Graphic





*“My humanity is bound up in yours, for we can only
be human together.”*

– Desmond Tutu

PHYSICAL WELLBEING

Physical wellbeing is fundamental to daily functioning and can change throughout the lifespan, as different events and environments can impact our physical wellbeing. Regularly monitoring our physical wellbeing is vital for physical wellbeing and is the foundation for healthy functioning in other areas. Many daily activities that promote physical wellbeing also promote mental wellness. Essential elements of physical fitness include medication, sleep, nutrition, sensory and motor functioning, and physical activity. Interventions targeting these aspects of physical wellbeing can improve outcomes when implemented alongside careful monitoring and encouragement, supporting overall wellness

Medical professionals, such as physicians or nurse practitioners, are often the first point of contact for individuals when health concerns emerge, and they play an essential role in the ongoing monitoring of physical wellbeing across the lifespan. Their position allows medical professionals to advocate for their patients and facilitate communication and collaboration with other healthcare providers.

Ongoing communication and collaboration can help to ensure that individual physical health needs are promoted, adequately addressed, closely monitored, and understood by all.



FASD-Informed

Individuals with FASD experience higher rates of physical health issues compared to the general population, and these issues may emerge at younger ages than what is typically observed (Hanlon-Dearman et al., 2015; Kable et al., 2021; Mela et al., 2020).

Early and continued support is critical in managing the physical wellbeing needs of individuals with FASD. Assembling a multidisciplinary and integrated team of care to target different areas of physical health is the gold standard in supporting individuals with FASD to live healthy lives (Massotti et al., 2015; Pei et al., 2021).

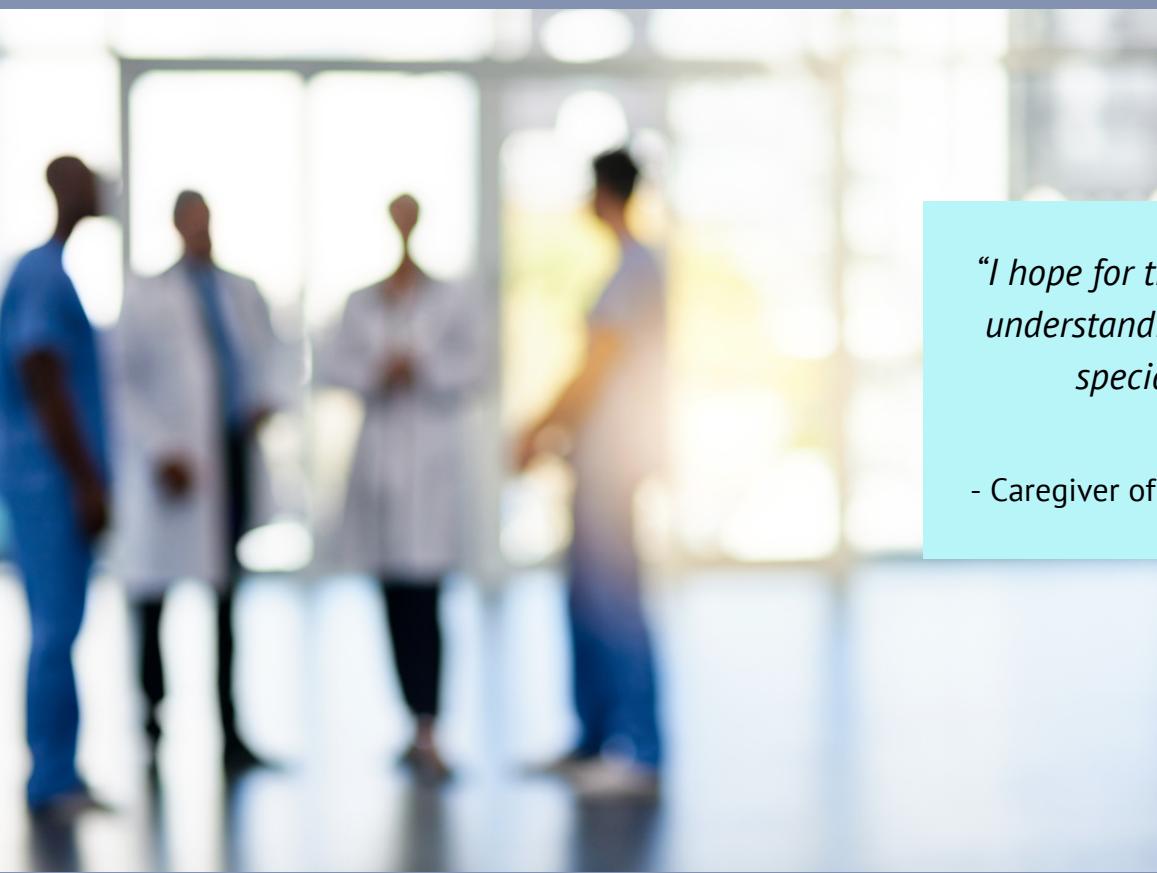
FASD as a Whole-Body Diagnosis

Individuals with FASD develop differently than individuals without FASD, and understanding how FASD can impact multiple areas of functioning is necessary for early diagnosis and providing appropriate support. Individuals with FASD are 100x more likely to be diagnosed with physical health conditions than the general population (Himmelrich et al., 2020). It is essential that physicians are knowledgeable about FASD and its impacts on all areas of physical wellbeing.



Physicians and other medical practitioners may find the following '**Lay of the Land: Fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis**' book chapter to be a helpful resource:

<https://www.taylorfrancis.com/chapters/edit/10.4324/9780429203121-14/lay-land-myles-himmelreich-lutke-emily-travis-hargrove>



"I hope for there to be a lot more understanding and doctors who specialize in FASD."

- Caregiver of an individual with FASD

Collaborative Care

Collaborative care and empowering individuals with FASD to understand their health needs and advocate for their health can improve their ability to live healthy lives. Individuals with FASD are more likely to experience higher rates and earlier onset of physical wellbeing concerns, which can complicate diagnosis and treatment (Himmelreich et al., 2020).



Dr. Hanlon-Dearman and colleagues (2015) created a guide for medical professionals managing the complex health concerns experienced by individuals with FASD. Although this document focuses on children and adolescents, it can be used across the lifespan, covering critical components of healthy functioning that are important to monitor. The guide can be found here:

<https://www.jptcp.com/index.php/jptcp/article/view/275>.

Brain-Body-Environment Interactions

Exposure to environmental factors as early as in the prenatal period can impact an individual's response to stress later in life. Individuals with FASD have brain-based differences resulting from prenatal alcohol exposure, increasing their vulnerability to stressful situations and environments. Difficulties coping with stress may implicate many of the systems in the body and can impact overall physical wellbeing.

The interaction between brain-based differences and stressful environments can influence many essential components of physical and overall wellbeing. For example, stressful environments can disrupt an individual's ability to have a good night's sleep, which is vital for the brain and body to function adaptively. Disrupted sleep impacts physical health and can interfere with an individual's mental wellbeing.



Health Education

Health education is important because understanding the benefits of engaging in healthy activities in daily life can increase a person's engagement in these activities. Medical practitioners and other healthcare workers can empower individuals with FASD, their caregivers, and other care team members by connecting them with referrals and information helpful to understand their unique needs. In this way, health education can provide a more complete context for the medical challenges an individual may experience and help them better understand themselves and how to promote their physical wellbeing.

Another critical area of health education is avoidance of substance use during pregnancy, which should highlight the importance of abstaining from alcohol and other substances in a manner that people with FASD can understand. Supportive others have noted that sexual health is an essential area of consideration when working with people with FASD who may not have access to this education, resulting in an increased risk for sexually transmitted diseases and other concerns related to sexual health and wellbeing.



Education on sexual health and wellbeing is a fundamental right for all and can begin as early as late childhood. Misinformation and misconceptions about pregnancy, sexually transmitted diseases, protection, and consent contribute to poor sexual health outcomes, so early education is essential.

Sex & U provides information and resources for sexual and reproductive wellness which can be found here: <https://www.sexandu.ca/>

Up to date, evidence-based information related to sexual health and wellbeing for caregivers, educators, and teachers of children from birth up to 18 years of age can be found here: <https://teachingsexualhealth.ca/>

Moving Together

Sleep

Sleep is essential to our physical health, and maintaining a healthy and consistent sleep schedule is especially important for individuals with FASD. Sleep's importance is comparable to recharging a battery-powered device, such as a phone, at the end of a day. A phone needs to be adequately charged for use the following day. If the battery is drained, the phone will not be functional. Similar restorative and recharging processes occur within our bodies and minds while sleeping. For example, sleep helps our brain to clear out toxins and waste, enables memory consolidation, and gives our muscles time to rest and recover.

Regardless of age, implementing a **consistent bedtime routine** can help to signal to the body that bedtime is approaching. Learning about sleep hygiene can help identify strategies that support healthy and restful sleep, such as:

- avoiding wakeful activities in bed, such as working, reading, eating, and watching TV,
- ensuring your bed is a space solely devoted to sleep,
- taking a warm bath,
- drinking a calming tea,
- meditation,
- creating a calm, quiet, and comfortable space to sleep in, or
- avoiding naps too close to bedtime.

Dr. Hanlon-Dearman and colleagues have adapted a **Better Nights/Days program for use with children with FASD**. Information about the program and additional resources can be found here:

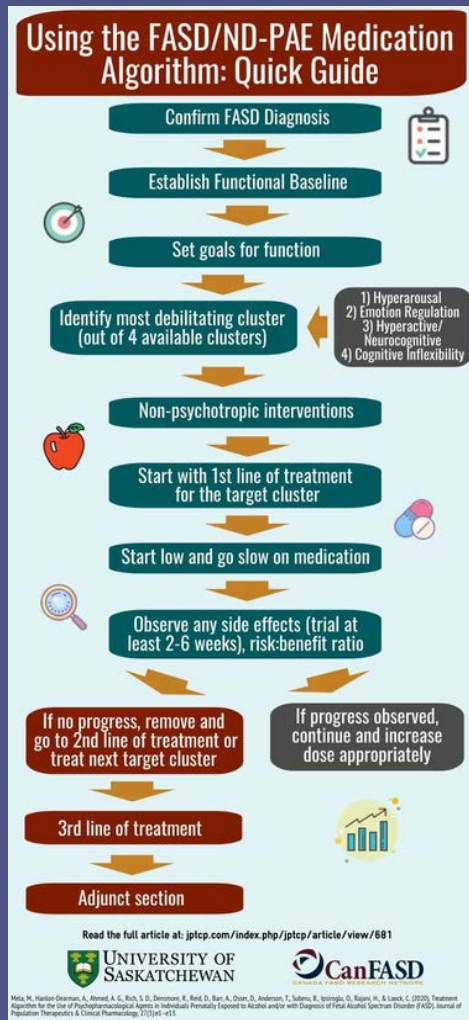
<https://ndd.betternightsbetterdays.ca/>



Medication

Medication can effectively treat many health symptoms and improve the quality of life for people with FASD. However, because it can be difficult for physicians to find the best-suited available medication for individuals with FASD, medication decisions should be based on each person's unique physical and mental health needs, diagnoses, and common symptom clusters, including hyperarousal, hyperactive/neurocognitive, cognitive inflexibility, and affect/mood regulation (Mela et al., 2020).

! A team of researchers produced a tool as a conversation starter and guide regarding prescribing medications for physicians: <https://canfasd.ca/algorithm/>



Nutrition

Proper nutrition is fundamental to overall health. The key to developing healthy nutrition habits is understanding that all food serves as energy-building blocks our body needs to function, and a healthy relationship with food can set the foundation for lifelong nutritional wellbeing. Children with FASD are more likely to engage in abnormal eating patterns and are thus at higher risk of nutritional inadequacies and delayed growth (Amos-Kroohs et al., 2015; Werts et al., 2014). If nutritional problems are identified, a referral may be made to a dietician, an occupational therapist, or a multidisciplinary feeding team (Hanlon-Dearman et al., 2015). Additionally, it is possible that medication can affect appetite, so regular monitoring and management with a professional is essential.

Regular family meals can promote family cohesion. By involving each family member in the dinner-making and eating process, everyone contributes to the food they are eating. Engaging in cooking activities can also nurture relationships and connections between family members, preserve cultural traditions, and bring joy and satisfaction.

Sensory and Motor Functioning

Sensory input can be experienced differently depending on an individual's brain-based differences. Sensory dysregulation refers to a lack of or extreme sensitivity to any of the five senses, including touch, light, sound, taste, and smell. These sensitivities can make it challenging to navigate and function within environments like work, home, and school.

Motor skills are an essential part of our daily activities; gross motor skills help us to walk, play sports, and exercise, whereas fine motor skills help us tie our shoes, draw, and button our shirts. Motor skills are likely to vary by person, and our environment and opportunities to practice can impact their development.

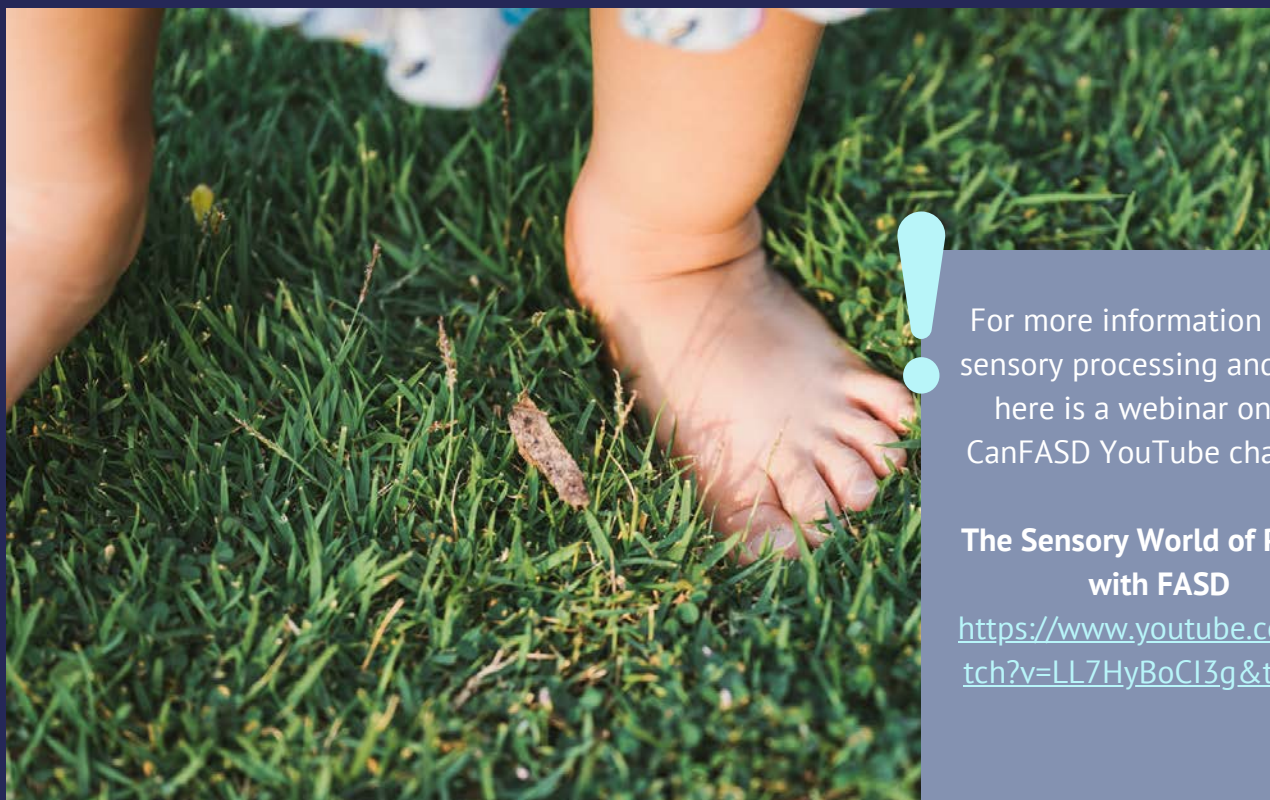
Medical professionals may refer individuals with FASD who have sensory and motor difficulties to **occupational therapists**. Occupational therapists can work alongside families to develop strategies and identify environmental factors that can be adapted to empower individuals with FASD to meet their goals and live healthy and happy lives.

Common strategies and tools to support sensory and motor functioning include:

- fidget toys,
- noise-cancelling headphones, and
- chewing gum.

Environmental supports to accommodate the sensory and motor needs of individuals with FASD can include:

- creating **opportunities** to engage in movement during the day, like walking,
- offering different seating **options**, such as an office chair or stability ball, or
- limiting fluorescent **lighting** when possible.



For more information about sensory processing and FASD here is a webinar on the CanFASD YouTube channel:

The Sensory World of People with FASD

<https://www.youtube.com/watch?v=LL7HyBoCl3g&t=460s>

Physical Activity

For individuals with FASD, an active lifestyle has been linked with improved executive functions, including working memory, attention, and inhibition (Varigonda et al., 2020). Daily cardio, such as riding a bike or walking to school, also stimulates the brain and body so we feel healthy and engaged throughout the day. This can, in turn, promote a better night's sleep because the body is active during the day, which leads people to feel more refreshed the next day and can improve mood, energy levels, attention, and focus.

Physical activity can have cascading benefits, such as:

- hormonal impacts,
- endorphins,
- improved mood,
- pain relief, and
- cardiovascular health.

Physical activity can also promote social skills, responsibility, and self-exploration. Extracurricular or group activities incorporating physical activity, such as running clubs or team sports, present opportunities for peer engagement that promote social functioning (Jirikowic et al., 2010).

Engaging in physical activity that includes teamwork or collaboration may increase the engagement of people who enjoy socializing and connecting with others and the likelihood that they return to that activity again in the future.



Stay Tuned!

Research around the impacts of physical activity on children and adolescents with FASD is ongoing!

Watch for upcoming research about the effects of physical activity from Dr. Mela and colleagues.



Dental Health

Maintaining overall dental health care is essential to overall physical wellbeing. If proper dental check-ups and procedures are neglected, this can lead to a range of health problems beyond the mouth. For example, digestive problems may emerge if chewing is impacted due to dental problems. Children with FASD, for example, may be at a higher risk for poor oral health outcomes requiring more extensive treatment (Da Silva & Wood, 2020).



"I think she will grow into exactly who she is meant to be, which is a pretty great person."

-Caregiver of an individual with
FASD

ATTACHMENT & RELATIONSHIPS

At our core, human beings are social creatures. We are wired to connect to others as a natural part of our development and increased exploration of our environment and world. We use the word 'attachment' to describe the outcomes and processes associated with early life bonding experiences with caregivers. We have learned that children who experience stable and reciprocal early relationships tend to have secure attachments to their caregivers - and consequently explore and interact with the world around them with greater confidence. Other early life circumstances in which children experience inattentive parenting, instability, separation, loss, and chaotic or disrupted environments can lead to insecure attachment relationships. Through insecure relationships, children learn that the world is not always predictable and that, at times, they may not feel safe. Early attachment relationships impact a child's ability to trust others, manage emotional responses, and establish interdependence and positive self-worth.



As such, attachment experiences are a prime contributor to relationships – across the lifespan at every stage of development. We have learned that healthy relationships can increase attachment security at **any stage** of development.

Even if an individual has experienced insecure attachments and, as a result, feels that the world is unpredictable, attachment security can be formed later in life by new experiences, interventions, family cohesion, and other supportive relationships. The core to this domain is that attachment and relationships are foundational to safe exploration of the world, emotional security, and skill building to interact and develop friendships with others. If the attachment platform is unsteady, the relational structure will also be unsteady, like a foundation in a home. Attachment relationships and other domains of healthy functioning, such as physical health, form our basement.

FASD-Informed

The brain develops through complicated interactions between genetics and brain structure, environment, and experiences. For individuals with FASD, when brain-based differences associated with prenatal alcohol exposure interact with environmental stressors, such as disrupted attachment experiences, this can uniquely impact attachment relationships with caregivers and other relational supports. For example, in infancy, the parenting behaviours of warming, soothing, cleaning, and calming create a set of sensory stimuli that helps the brain develop in a way that supports healthy social and emotional development. This development relies on attentive and nurturing caregiving in early childhood and opportunities to form and keep up with various relationships with other individuals across every life stage. Although disruption to attachment may impact social and cognitive development, building healthy relationships can continue to inform and influence attachment foundations throughout the lifespan.

Attachment & Brain Development

Attachment is closely linked to brain development. The amygdala plays a significant role in forming attachment bonds and social relationships because this part of the brain helps us remember past relationships, regulate our emotions, and contribute to our body's response to stressful or fearful situations. This link between the brain and environment is uniquely complex for people with FASD.



Did you know?

Individuals with prenatal alcohol exposure and FASD experience higher levels of adversity beginning as early as childhood (Flannigan et al., 2021; Lebel et al., 2019; McLachlan et al., 2015).

Children with FASD more frequently experience a range of adverse childhood experiences, including disrupted attachment (Kambeitz et al., 2019; Price et al., 2017).



Home

The home environment plays a crucial role in supporting attachment and relationships. A supportive home environment can be essential for lifelong relationship building and attachment. Children with FASD are overrepresented within the child welfare system compared with other populations. In one large-scale study, Burns and colleagues (2021) found that 32.8% of children with FASD were in the care of foster or group care. For children in the welfare system, common disruptions like relocation and changes in their guardianship/caregivers can affect multiple domains of functioning, including cognitive, social, and emotional development. Frequent relocations can prevent children with FASD from developing and maintaining long-term relationships within their home environment and caregivers. Similarly, changes to guardianship can impact the consistency, expectations, and boundaries experienced by children with FASD, which can further influence how they interact with others.

“The attachment we have finally formed where we can joke and laugh and know we’re okay, and where he will confide his concerns with me instead of hiding or confabulating.”

- Caregiver of an individual with FASD



From “Double Jeopardy” to Opportunity

The combination of brain-based differences to stressors with heightened risk of adverse experiences has been described as a state of “double jeopardy” for people with FASD (Coggins et al., 2007; 2009). Understanding these differences and impacts can help us know what kinds of support are needed to foster healthy attachment and relationships across the lifespan. A shared understanding of brain-based differences and exposure to adversity allows us to reframe interpretations and expectations for behaviours. It is also essential for intervention and supports to consider and leverage the strengths of individuals with FASD, who are often characterized as kind, compassionate, and caring, all of which may contribute to forming human connection (Flannigan et al., 2021). Armed with this knowledge, we can return to the basic principles of attachment and relationship to harness the power of this foundational developmental process as we tailor intervention, support, and growth opportunities to the unique needs of each individual with FASD.

Moving Together

Attachment-based support, education for caregivers, and family cohesion can have positive impacts for individuals with FASD and their families across all stages of development. Additionally, individuals with FASD and their families have communicated the need for interventions that leverage strengths and allow individuals to live authentically and establish meaningful relationships that contribute to overall health and wellbeing.



Fostering Caregiver-Child Relationships

Attachment-based therapy can help children with FASD develop healthy coping skills to support attachment relationships, family cohesion, and overall wellbeing. For example, parent-child interaction therapy, which includes behaviour education and coaching for parents, has decreased parent stress and problematic behaviour among children aged 3-7 years with FASD (Bertrand, 2009). Similarly, interventions developed through a dual attachment and trauma-informed lens have the potential to impact children with FASD and their families positively (Zarnegar et al., 2016). **Core components and goals** for this therapeutic approach include:

- creating **safety** in parent-child relationships and surrounding environments;
- expanding parental **responsiveness** to the needs of the child;
- promoting parents' ability to **balance** their own needs with their child's; and
- enhancing **communication** between parents and their children (Toth et al., 2018).

Many adolescents with FASD have also experienced disrupted attachments, and it is essential to provide opportunities to re-establish meaningful and secure relationships with caregivers and other important people in their lives. Interventions have been developed that promote security between teens and their caregivers, such as the **Connect Program**, which is intended to increase caregivers' understanding of the behaviours they see and connect them to the underlying attachment circumstances contributing to these behaviours. In doing so, the program allows for the development of attachment and trauma-informed parenting skills that ensure the provision of a haven and secure base (Moretti et al., 2017).



For your consideration...

Sometimes, grandparents and great-grandparents are involved in raising children that they may not have expected to. Services and policies that seek to support individuals and families with FASD should create space to consider and respond to the needs of non-bio parents acting as caregivers.



Facilitating Family Cohesion

The family environment is another essential factor to consider in effectively supporting individuals with FASD (Jacobson et al., 2004; Reid et al., 2022; Streissguth et al., 2004). Interventions that enhance family understanding of behaviours and incorporate family expertise are linked to improved family cohesion and promote a greater sense of hope for individuals with FASD and their caregivers (Petrenko & Kautz-Turnbull, 2021). For example, **The Families Moving Forward (FMF) program** is a consultation program which emphasizes the importance of leveraging environmental supports to increase caregiver self-efficacy and cognitive appraisal, improve child adaptive behaviour, and decrease overall problematic behaviour (Petrenko et al., 2017; Petrenko et al., 2019). Similarly, the **Parents Under Pressure program** has successfully improved caregiver understanding of FASD and associated brain-based differences through an integrated home-based intervention. The program also provides caregivers with skill-building opportunities to work with their children with FASD to build mindfulness and self-regulation skills to manage strong emotions.

"I'm learning and growing as a parent. She is learning and maturing. We both seem committed to the process of helping her succeed. It's a slower pace and looks different than I expected it would, but nevertheless it is good and gives me hope."

- Caregiver of an individual with FASD

Meeting Caregiver Needs

Families and caregivers are excellent sources of information regarding strengths and resiliency factors that may be incorporated into intervention planning for individuals with FASD. Stable and consistent interactions that foster positive attachment with caregivers, peers, teachers, and supportive others are essential for healthy relationships.

Here is a resource guide for caregivers of individuals with FASD: <https://canfasd.ca/wp-content/uploads/2018/03/Caregiver-Resource-Guide-FASD-March-2018.pdf>.



Mentoring and coaching caregivers is essential for increasing caregiver autonomy and success in supporting their children and adults with FASD. Mentors and coaches can be especially beneficial in cases where caregivers have limited knowledge or experience in caring for the unique needs of an individual with FASD. Mentors can work with caregivers to facilitate positive change and increase stability in the home environment. For instance, the Coaching Families program offers mentorship opportunities for caregivers of children with FASD, including FASD education and access to services and advocacy support (Leenars et al., 2012). Central to this program is establishing a solid working relationship between mentors and caregivers through which self-care strategies are encouraged to offset breakdowns within the family unit. Caregivers who completed this program have reported decreased stress and an increased capacity to access supports independently and needs related to housing and transportation, family parenting, community development, and community resources (Leenars et al., 2012).

Did you know?

Caseworkers provide *critically important* resources for children in child welfare settings, and it is essential that caseworkers receive necessary FASD-informed training and support, such as lower caseloads, to effectively fulfill their role.



SOCIAL COMPETENCY

Social competency is a dynamic, evolving set of skills necessary for engaging in positive interactions and maintaining positive relationships with others throughout one's lifespan. Social competency requires integrating complex skills across multiple areas of functioning, including cognitive, emotional, and behavioural abilities. Social functioning can be challenging because it requires us to draw on different areas of knowledge and abilities, including social cues, past experiences, and interpersonal sources of information. Combining external information with our unique social abilities can lead to a broad spectrum of potential responses within social interactions (Kully-Martens et al., 2011). Social skills are essential to adaptive functioning, and leveraging strengths around social functioning can improve one's day-to-day functioning and support skills necessary for education, employment, and interdependence (Matson, 2017).




FASD-Informed

In one study, 58% of individuals with FASD reported experiencing difficulties with social competency when interacting with others (Millians, 2015). Some brain-based differences associated with FASD relevant to social interaction may include the ability to regulate emotions, recognize others' emotions, language and communication abilities, and actual execution of social skills. Social interactions also require the application of executive functions, including inhibition, working memory, and organization. Establishing a shared understanding of these differences prepares us to provide proactive and informed support when individuals with FASD struggle socially. Despite potential challenges, individuals with FASD are highly motivated to connect with others and are often described as friendly, helpful, and empathetic (Flannigan et al., 2021).

Emotion Regulation & Recognition

Managing our emotions and responding to the emotions of others are essential aspects of social interactions. Knowing how to regulate our excitement, sadness, or anger is necessary to navigate a conversation, engage in an activity, or resolve a conflict. When dysregulated, we may present as 'out of control,' 'hard to deal with,' or 'too energetic.' On the flip side, recognizing emotion in others – are they angry, sad, or happy – is also part of gauging a conversation, establishing reciprocity, and expressing empathy. Individuals with FASD may need support understanding various perspectives, solving complex social conflicts, and developing positive peer relationships (Kerns et al., 2016; Millians, 2015).



"She is friendly and funny and kind. She loves to help. She is curious. If she has someone who supports her to use those [skills] and not take advantage of her she can do so much."

- Caregiver of an individual with FASD

Language & Communication

Language development is also critical to social competency, as communicating effectively is integral to social interactions (Mundy & Sigman, 2015). Effective communication includes understanding others and clearly expressing ourselves (Niemiec, 2020). For people with FASD, language development can be slower than typically observed (Vega-Rodriguez et al., 2020), meaning that many individuals will likely need help navigating communication challenges. As we develop from childhood into adolescence and adulthood, social interactions become increasingly complex, abstract, and reliant on solid communication skills. Providing individuals with FASD with accommodations and strategies for communication can help support their social competency.



Social Skills

Individuals with FASD have many social strengths, such as engaging and initiating social interactions with those around them (Millians, 2015) and valuing empathy and compassion towards others (Niemiec, 2019). People with FASD are often described as friendly and outgoing, yet they may act without awareness of social norms and subsequently may be teased by peers (Kully-Martens et al., 2011).

Helping children and adolescents with FASD develop their social competency skills and facilitate effective social interactions requires clear discussions of boundaries and expectations. For example, verbal prompts and frequent reminders of social cues can support healthy exploration of the environment and relationships with others. Opportunities to practice social behaviours are crucial for individuals with FASD to develop social competency and maintain positive relationships (Petrenko & Alto, 2017).

Caregivers and supportive others need to work with individuals with FASD to build their social skills. Working collaboratively through co-creating strategies to successfully navigate social environments and relationships can contribute to positive outcomes in this domain. When co-creating strategies, it is essential to do with, not for. This allows individuals with FASD to develop a sense of self-efficacy or a belief in their ability to solve social problems they may encounter in their environments. Taking this approach may involve helping people with FASD move closer to independently applying learned skills through the process known as scaffolding.



For your consideration...

People with FASD often require *explicit, direct* instructions and prompts that focus on the goal behaviour rather than what not to do when learning and practicing their social skills.

Try Saying...

“Please go back to your place in line . We all need to wait our turn”

“Let’s keep the conversation respectful. Jokes that may offend or hurt others are not acceptable”

“Please give me some space. It is important to respect personal boundaries”

Instead of...

“You just cut in front of everyone in line.”

“Your jokes are offensive and inappropriate.”

“You’re invading my personal space.”

Environmental Influences

When supporting the social development of people with FASD, it is essential to consider their perspectives, priorities, and the influence of environment and past experiences:

- People with FASD are more likely than those without FASD to struggle with social skills, such as setting and respecting appropriate interpersonal boundaries. These difficulties can lead to misunderstanding, withdrawal, and conflict (Kully-Martens et al., 2011).
- Environments that include supportive adults, close family members, and other opportunities for interpersonal connection are vital for fostering social competency.
- Children often learn through observing and modelling (Kully-Martens et al., 2011). For children and adolescents with FASD, direct, hands-on approaches to learning social skills may be required to ensure knowledge and skill retention.

People with FASD desire meaningful connections and contributions within their relationships. Relationships and friendships are more meaningful when we feel that others understand our unique perspectives and experiences (Copeland, 2002). This means that supportive others must better understand the unique experiences of people with FASD we are trying to support and how these experiences inform social skills and relationships (Copeland, 2002).



Moving Together

At Home

The home environment plays a crucial role in helping to develop social competency and families can play an essential role in shaping the social competency of children with FASD. Children with FASD are overrepresented within the child welfare system compared with other populations. In one large-scale study, Burns and colleagues found that 32.8% of children with FASD were in the care of foster or group care (Burns et al., 2021). For children in the welfare system, common disruptions like relocation and changes in their guardianship/caregivers can affect social development. Frequent relocations can prevent children with FASD from developing and maintaining long-term relationships within their home environment and caregivers. Similarly, changes to guardianship can impact the consistency, expectations, and boundaries experienced by children with FASD, which can further influence how they interact with others.

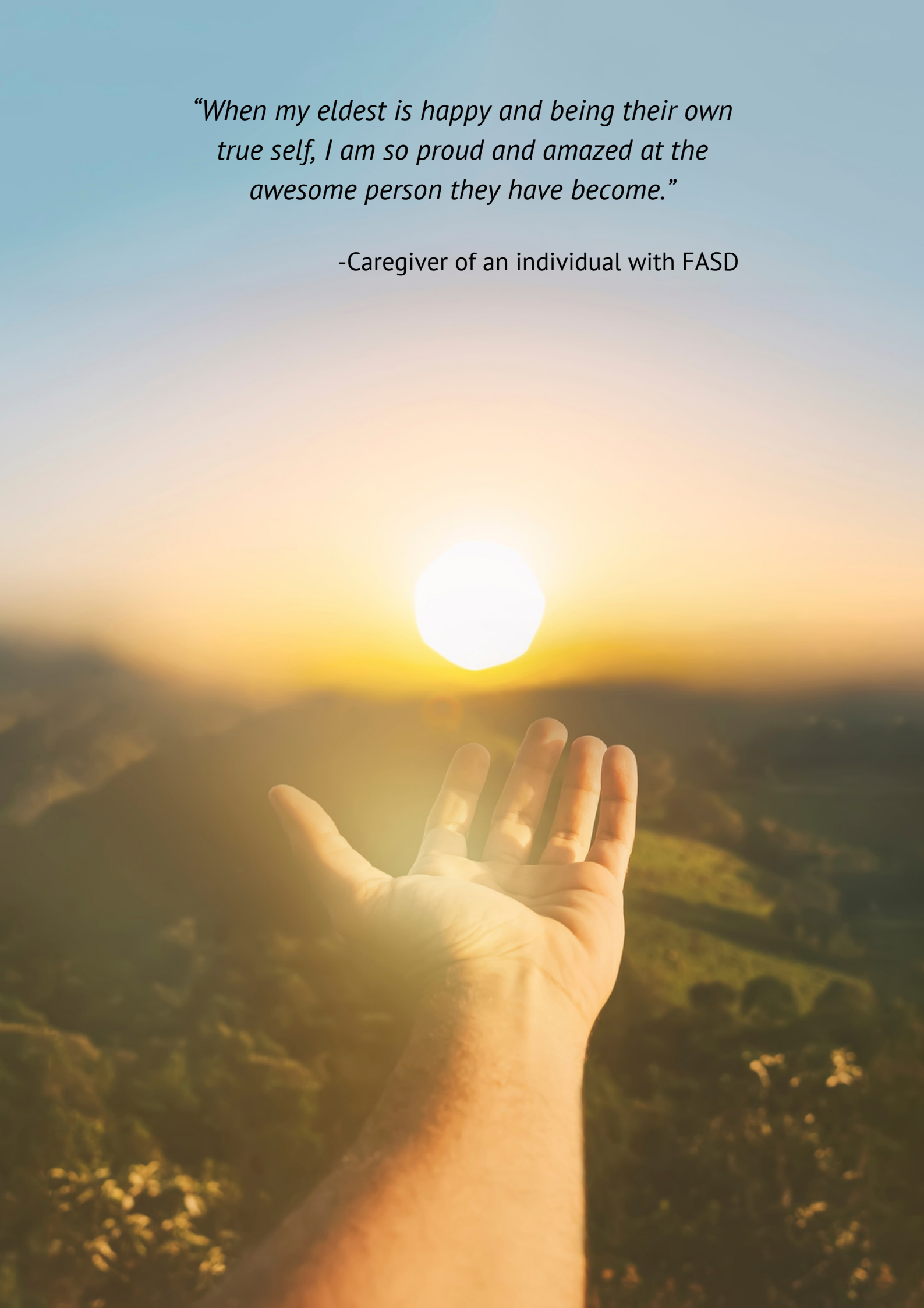
At School

School also plays a critical role in childhood and adolescent social development. Children and adolescents in Canada spend most of their waking hours at school among their peers. In one study, 55% of students with FASD were reported to display disruptive behaviours in the classroom (Millians, 2015). Children and adolescents with FASD often require direct training to inform their social skills, including regulation and communication. Clear instructions, mentoring, and opportunities to practice are practical strategies that can be used to support social functioning. Schools where social skills are promoted through direct interventions support students' social competency, which can have a lasting influence on long-term outcomes across the lifespan (Jackson et al., 2020).



“When my eldest is happy and being their own true self, I am so proud and amazed at the awesome person they have become.”

-Caregiver of an individual with FASD



MENTAL WELLNESS

Mental wellness is foundational for quality of life and includes both emotional and psychological aspects of wellbeing. Mental wellness is a psychological state that enables us to respond effectively to stressors and connect with others who support us in healthy living (World Health Organization, 2022). Many factors, including biology, environment, and age, influence our mental wellness. Mental wellness encompasses mental health and can look like connecting with others, regulating our emotions and behaviours, and engaging in activities and relationships that bring us fulfilment and joy. Although individuals with FASD are more likely to experience mental health needs than their peers without FASD, evidence-informed and proactive support can help address areas of need and highlight strengths to facilitate enhanced mental wellness for individuals with FASD and their families. Armed with this knowledge, we recognize the importance of monitoring mental health challenges and people with FASD understanding and having access to available supports. To achieve this goal of improved wellness for people with FASD, we must work to develop a shared understanding of FASD, the critical behaviours to observe and respond to, as well as the evidence-informed interventions and supports that are needed.



FASD-Informed

FASD is a complex neurodevelopmental disability where biological and environmental risks interact uniquely to impact mental wellness (Pei et al., 2011; Streissguth et al., 2004; Weyrauch et al., 2017). Additionally, prenatal alcohol exposure is closely tied to stress responses and may increase the risk that individuals with FASD develop physical and mental wellness concerns later in life, regardless of the extent of stress exposure.

By understanding the intersection between prenatal alcohol exposure and mental wellness, we are best equipped to proactively monitor and support mental wellness. Seeking out environments and strategies that reduce stress, address mental health concerns, and enhance feelings of autonomy and competency can support mental wellness for people with FASD. In addition, identifying and nurturing strengths, even considering areas of concern, can provide a balanced approach to mitigating stress and fostering positive emotional states.



For more information, you can refer to the following position paper regarding FASD, stress, and mental health: <https://canfasd.ca/wp-content/uploads/2016/05/FASD-Stress-and-MH-EN.pdf>

In considering the mental wellness of individuals with FASD, three broad core needs and opportunities have been identified:

- **life promotion,**
- **stigma,** and
- **reframing perspectives.**



For your consideration...

People with FASD are unique and complex. The intersection of brain-based differences, exposure to adversity, and mental wellness comorbidities may lead to an increased risk of system involvement, including the justice system. At present, there is no clear consensus regarding prevalence rates of FASD within the justice system; however, it is speculated that individuals with FASD are overrepresented (Flannigan et al., 2018). Many of the difficulties associated with justice involvement are not unique to FASD, and importantly, many people with FASD do not end up in the justice system (Pei et al., 2018).

It is **critical** to continue to educate professionals within the justice system on FASD, associated behaviours, and available interventions, strategies, and supports to offset overrepresentation and promote healthier outcomes for those involved.



“She remains happy to be alive and genuinely looks forward to her own future.”

- Caregiver of an individual with FASD.



Life Promotion

Serious concerns may accompany struggles with mental health, which can be hard to talk about and frightening for families. Suicide is one such concern. Individuals with FASD may be at increased risk for suicide because of the complex interactions between prenatal alcohol exposure and environmental adversities (Flanigan et al., 2022a; Flannigan et al., 2022b; O'Connor et al., 2022; Pei et al., 2011). In understanding and responding to this concern, one local community has provided a goal-oriented, strengths-based approach – **life promotion**. Life promotion addresses suicide by promoting approaches that strengthen how people feel connected to life (Métis Nation of Alberta, 2022). Life promotion helps people experiencing suicidal ideation develop experiences, relationships, and social connections that re-engage them with community, culture, and identity and, in turn, living. Taking a life promotion approach allows supportive others to recognize that distress and suffering exist in the context of life and, rather than focusing on the individual and their problems, enables us to tap into community strength and capacity.



The Métis Nation of Alberta (2022) released a **Life Promotion Resource** to support developing, implementing, and evaluating programming that connects young people to life. This guide can also support others wishing to promote life and provides resources, action items, and services:

<https://albertametis.com/app/uploads/2022/03/Life-Promotion-Guide-V5.pdf>.

Stigma

For people with FASD, the stigma associated with their diagnosis may interfere with seeking and accessing mental health services. At the broadest level, alcohol use is generally highly stigmatized within social systems, to an extent that may be even greater than other physical and mental health conditions (Corrigan et al., 2019; Green et al., 2020). The stigma associated with alcohol use during pregnancy is linked to decreased access to services, including those that target mental wellness and substance use (Blakey, 2012; Ruttman & Hubberstey, 2019). Individuals with FASD, and by association their families and social support networks, experience stigma related to the diagnosis, associated behaviours, and other areas of functioning that may be perceived as different from others (Corrigan et al., 2019). Public perceptions of individuals with FASD can sensationalize individual behaviours and view all people with FASD as the same, and fail to consider the potential for growth through intervention and support (Aspler et al., 2019).

However, **the story does not stop there**. Increasing our understanding of the impacts of stigma and public perceptions of FASD on an individual's mental wellness and ability to access support can reduce barriers and support healthy outcomes. Increasingly, people with FASD and their caregivers, are speaking out and creating new narratives. Through continued conversations with individuals with living experiences with FASD combined with the recognition of the many strengths that individuals with FASD possess, we can work together to remove the stigma and enable others to see people with FASD as the resilient individuals that they are. The onus is on all of us to be part of this evolution.

Reframing Perspectives

Understanding the unique strengths and needs of individuals with FASD develops insight into factors that may disrupt mental wellness or aggravate mental health needs. **Recognizing the underlying factors contributing to specific behaviour is vital for helping individuals find healthy ways of navigating stressful environments and situations:**

- Cognitive differences associated with FASD may be exacerbated when daily challenges elevate stress or when an individual with FASD struggles to generate solutions or strategies to manage daily demands and difficulties. For example, difficulties with verbal expression or comprehension, processing speed, and impulsivity may lead to challenges with navigating daily activities, such as social interactions, completing tasks, or engaging in personal hygiene activities.
- Subtle changes to tasks or the environment can significantly impact stress levels for an individual with FASD – which may confuse those around them.
- Differences in sensitivity to body states like hunger or fatigue may further impact a person's unique cognitive skills and ability to access strengths consistently. As a result, these difficulties for people with FASD may not always be apparent or understandable to others, which can create high stress and frustrating situations.



Moving Together

Supporting mental wellness through services and strategies may look different for each person with FASD and can vary by age. Support may be **preventative**, **targeted** (e.g., strategy development, specialized mental health support), and **contextualized** (e.g., environmental supports). Often, integrating all aspects of support helps facilitate proactive and responsive support that identifies a desired goal(s) for individuals. In all cases, to optimally promote mental wellness, strategies should be built upon both individual and community strengths.

Throughout the lifespan, individuals with FASD and their support systems need to monitor behaviours, identify underlying stressors, leverage personal strengths and resources, practice strategies that promote wellness, and reach out to mental health professionals as they work towards living healthy lives and achieving their goals.

Here is a **guide and tool-kit** to supporting mental wellness in individuals with FASD from CanFASD: <https://canfasd.ca/mental-health-toolkit/mental-health-toolkit-introduction/#1695990942772-1cb3e53c-696f>



Emotional Awareness

Learning and practicing strategies to check in on internal regulation states can help individuals identify their feelings and make changes to reach their optimal regulation state instead of acting out with disruptive behaviours.

Strategies to support emotional awareness in children and adolescents with FASD include:

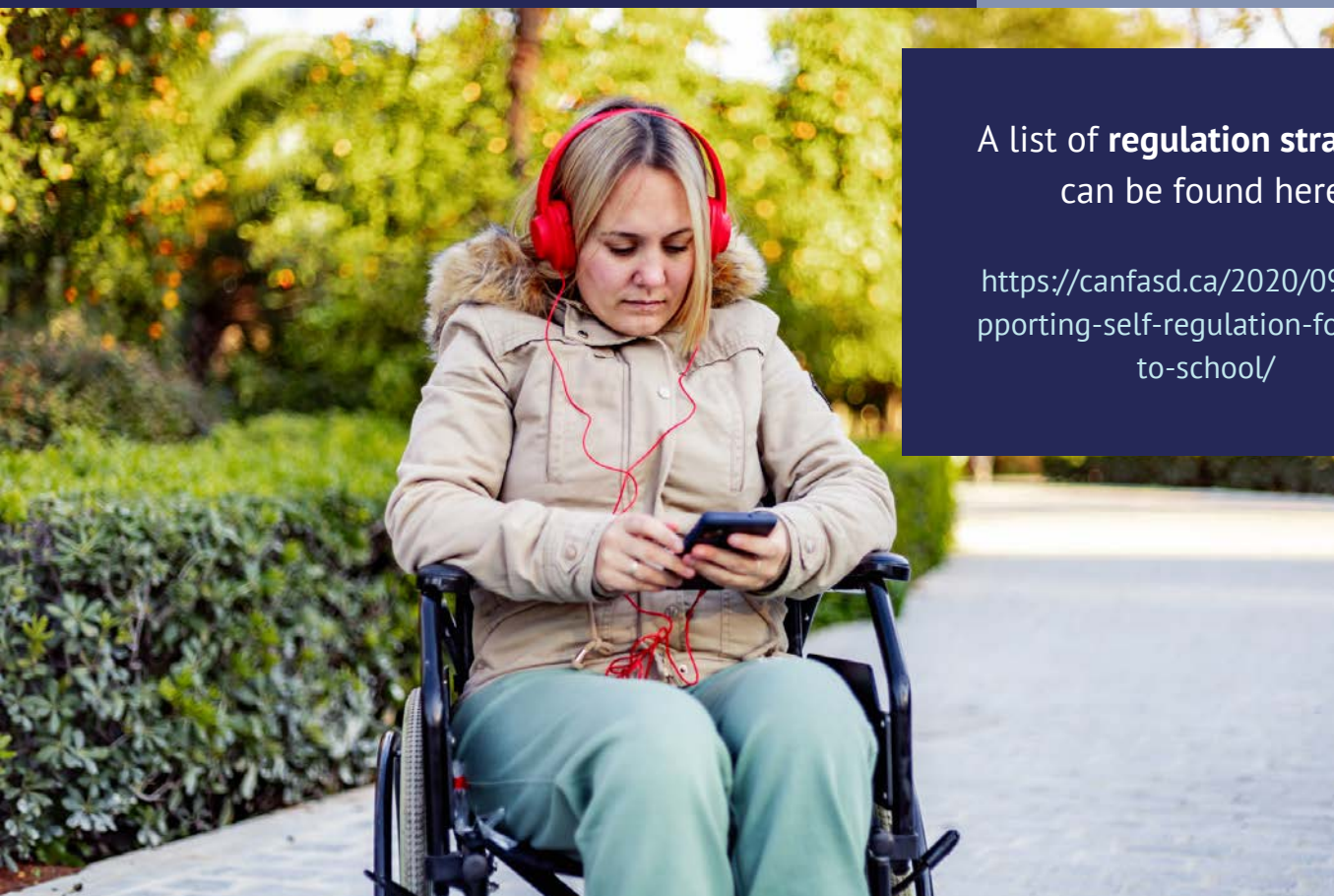
- Opportunities to practice identifying the emotions of others, either through media or people they can observe in their environment, such as parents, siblings, friends, teachers, and supportive others.
- Modelling or acting out different emotions, such as anger, happiness, and sadness, can help children and adolescents learn what different emotions might look like in other people and themselves and, in turn, support their emotional awareness.
- Implementing a visual tool to express their internal emotional state, like a speedometer in an automobile, a thermostat, or emojis to help children and adolescents with FASD identify how they are feeling to themselves and explain it to others.

Regulation

For people with FASD to navigate daily life, they need to be able to monitor their thoughts and feelings and manage their behavioural and emotional responses - or self-regulate - so they can act in ways that meet environmental demands. When faced with stress, regulating emotions can be challenging; in these moments, we may act out or withdraw and avoid tasks. However, healthy coping can be encouraged when we identify and work to strengthen supportive relationships. First, we need to create supportive environments, then a shared understanding of what dysregulation may look like, and finally, co-creation of strategies may occur. Starting with some regulation ideas and working with individuals with FASD to evolve these approaches allows us to tap into their insight and autonomy, build on strengths, and ultimately generate meaningful strategies.

Strategies can be explored across the five senses including:

- **Movement:** walking, running, yoga, spinning in a circle, wall sits, chair pushes.
- **Touch:** comfortable clothing, petting a dog or cat, gardening, playing with a sand tray, fidget toys.
- **Mouth:** chewing gum, drinking water, having a snack, hot tea, coffee, sweet and sour candies.
- **Sight:** looking at bright lights, dim lights, nature, art, TV, reading, drawing.
- **Hearing:** using noise cancelling headphones, headphones with music, ambient noise, pop music, nature sounds, and white noise.



A list of **regulation strategies** can be found here:

<https://canfasd.ca/2020/09/07/supporting-self-regulation-for-back-to-school/>




Metacognitive Strategies

Teaching children and adolescents with FASD metacognitive strategies has been found to improve their regulation, executive functions, and mental wellness (Makela et al., 2019). Metacognition is the process of thinking about our thinking and promotes the development of learning strategies and the generalization of skills and generates positive functional outcomes, which can promote mental wellness (Cicerone et al., 2011). These strategies can be used to successfully avoid roadblocks or any barriers that may interfere with an individual's behavioural goals. It is helpful for caregivers and other supportive persons to work with individuals to identify the goal and to co-create a plan and alternative strategies to meet behavioural goals. Through collaboration, individuals with FASD can develop a sense of self-efficacy or believe in their ability to solve their own problems.

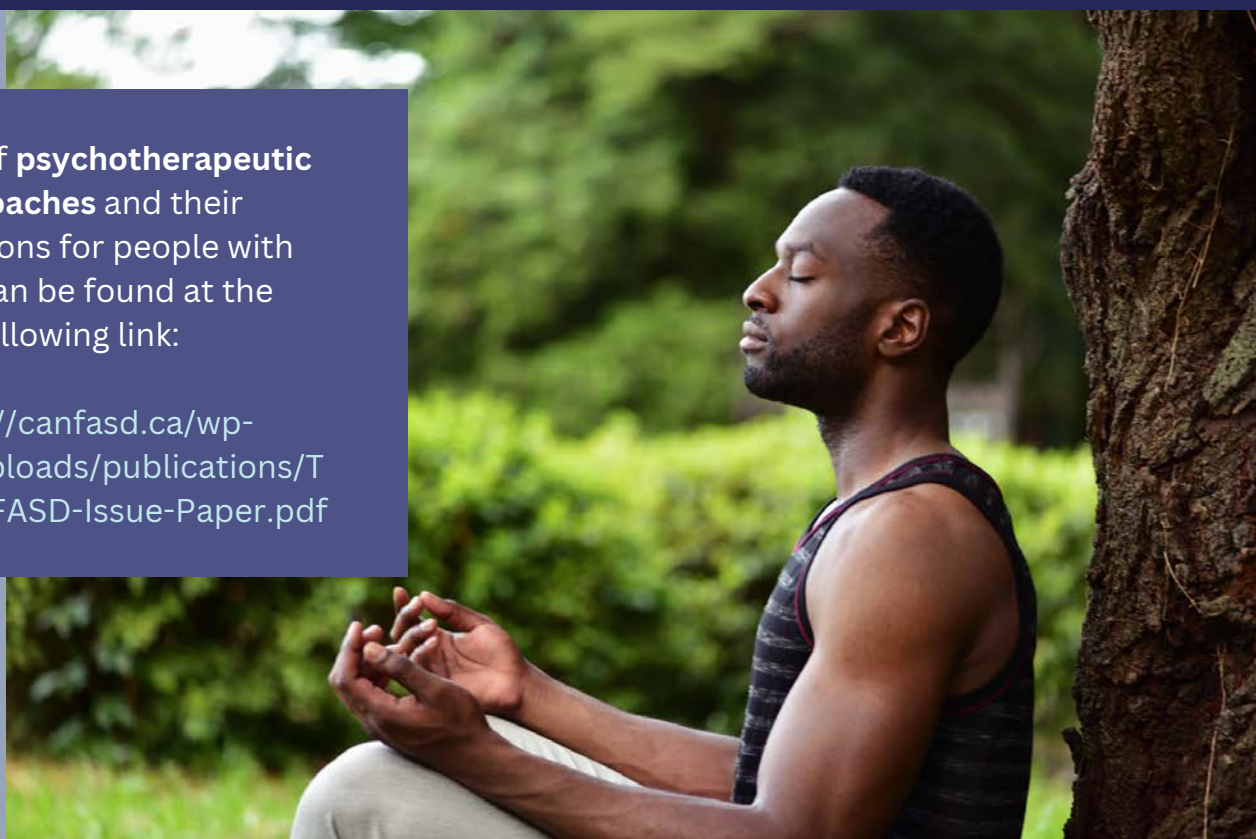
One metacognitive approach used with individuals with FASD is the **Focus and Plan, Act, Reflect (FAR) intervention** (Coles et al., 2015). This program explicitly teaches children to use specific metacognitive steps when approaching problems thoughtfully rather than responding impulsively. The first step children learn is to **focus and plan**, where they focus on the task and devise a plan to solve the problem. The child then **acts** intentionally and finally **reflects** on how the plan worked, if it was successful, and how it could be improved in the future (Coles et al., 2015). Children are then encouraged to perform the plan and reflect on what worked or did not (Coles et al., 2015). Other examples of metacognitive strategies may include:

- rehearsing different situations or conversations,
- chunking activities or tasks into smaller pieces,
- positive self-talk, and
- deep breathing.




A review of **psychotherapeutic approaches** and their applications for people with FASD can be found at the following link:

<https://canfasd.ca/wp-content/uploads/publications/Therapy-in-FASD-Issue-Paper.pdf>



Substance Use

Individuals with FASD are at increased risk for difficulties related to substance use (Flannigan et al., 2020; McLachlan et al., 2020), which can significantly impact physical and mental wellness, social relationships, and overall difficulties navigating healthy daily living. Like all wellness supports, treatment for substance use may look different for each person with FASD and vary by age. If substance use concerns emerge, individuals with FASD may benefit from a supportive person opening the door for conversation, engaging in collaborative safety planning, and helping them access FASD-informed treatment services.



Evidence-based practices to support people with FASD in treatment for substance use can be found in this CanFASD guide:

<https://canfasd.ca/wp-content/uploads/publications/Moving-Towards-FASD-Informed-Care-in-Substance-Use-Treatment.pdf>.



EDUCATION & SKILL BUILDING

Learning is a lifelong process that looks different for everyone. Education is an essential part of development that contributes to success in many domains of healthy functioning and is particularly relevant for employment and social functioning. Elementary and secondary schooling provides opportunities for learners to build adaptive and social skills in preparation for adulthood. Opportunities and skills learned in school can also offer a platform for pursuing other learning later in life, such as post-secondary education, applied training, or on-the-job work experience. In adulthood, learning continues in work and extracurricular environments through experience, mentoring, and targeted skill-building. Considering the unique strengths and needs of the individual creates a foundation for progress monitoring and planning – at all stages of life. A shared understanding of each person’s strengths and needs, along with proactive intervention planning, can support learners to achieve their goals and encourage them to learn and grow across the lifespan.





FASD-Informed

Each person with FASD has a unique set of strengths and resources that they can leverage to promote success in their learning environments. Many individuals with FASD are socially motivated, curious, and possess the ability to persevere through challenging situations. These areas of strength may contribute to self-efficacy, confidence in their ability to use their skills and meet their goals, and improved functioning in school and other environments (Flannigan et al., 2021). In addition to these documented areas of strength, people with FASD are also often reported to have interests in arts, music, and sports, which can be embedded into learning to support engagement (Brenna et al., 2017; Brules et al., 2018; Flannigan et al., 2021). With the necessary support and services to leverage strengths and target individualized needs, people with FASD can experience successful education and skill-building opportunities to help them meet their goals across their lifespan.

Hands-On Learning

Interactive approaches include instructional methods and strategies that actively engage students in learning. These approaches to learning emphasize hands-on experiences, student participation, and collaboration, and are linked to better outcomes throughout the lifespan for individuals with FASD (Flannigan et al., 2021; Kautz-Turnbull et al., 2022).

“If she can get a strengths and skills-based education, she has lots of potential to have a meaningful job and life!”

- Caregiver of an individual with FASD



Did You Know?

Training in our educational communities can help foster healthy outcomes within academic contexts for children and adolescents with FASD.

CanFASD offers flexible online training resources for educators and other professionals!

<https://canfasd.ca/online-learners/>

Understanding Differences

Individuals with FASD have brain-based differences and environmental and social experiences that can impact learning and behaviour in educational settings. Understanding these unique areas of need is a first step towards building **a goal-oriented plan to meet educational goals and contribute to successful learning opportunities** for individuals with FASD:

- Individuals with FASD often have difficulties with **executive functions**, which are related to many higher-level mental processes, such as memory, planning, self-regulation, and social skills (Kully-Martens et al., 2012; Kautz-Turnbull et al., 2021).
- **Brain-based differences** may impact classroom performance, learning, and task completion, such as forgetting to turn in homework, losing track of deadlines, and producing messy or incomplete work. Also, difficulties with emotion regulation may result in outbursts or meltdowns and lead a person to become overly nervous when facing learning challenges.
- Exposure to **environmental adversities** for people with FASD may impact relationship development with peers or connecting with educators, which may disrupt engagement and learning in educational and skill-building environments.
- Appropriate **interventions** are needed to address the impacts of brain-based and environmental challenges on learning and skill-building opportunities.

Moving Together

Educational interventions and supports that combine skill development and environmental support can equip individuals with FASD to meaningfully participate in their learning across the lifespan. This requires close collaboration between individuals, educational professionals, caregivers, and other supportive people. Through comprehensive assessment, supportive learning plans, FASD training, targeted interventions, and transition planning, people with FASD can successfully reach their educational and skill-building goals.

Assessment for Intervention

A comprehensive assessment is a critical first step in developing a supportive education plan for learners with FASD. This assessment should focus on evaluating various functioning domains that impact learning and behaviour, including cognitive abilities, language, adaptive functioning, memory, social-emotional and behavioural functioning, and academic achievement (Cook et al., 2016). Areas of strength and personal interests are also essential sources of information to consider when building a supportive education plan (Kully-Martens et al., 2021). Sharing and applying assessment findings allows educational staff, caregivers, and other supportive persons to understand learners' unique patterns of strengths and areas of need so that targeted interventions, strategies, and environmental supports can be implemented.

Assessment for intervention approaches allows us to develop a supportive plan that promotes growth and goal attainment for individuals with FASD who wish to participate in meaningful education experiences. **Emphasized within the assessment for intervention literature are four main ideas:**

- Assessment and intervention combined are **only as helpful as the recommendations** and supports that follow.
- The high variability in skills and needs for everyone with FASD requires that individualized assessment practices and processes focused on informing intervention practices are used to achieve the best possible educational outcomes.
- Recognizing the lived expertise of individuals with FASD and family members and involving educators as a team in the assessment process through decision-making and establishing intervention programming is vital (Pei et al., 2013).
- Important team members can include caregivers, family members, social service agency workers, primary health care providers, and supportive others.



Transition Planning in Learning Contexts

Transition planning is essential to promote successful educational and learning experiences across the lifespan (Lynch et al., 2015; McLachlan et al., 2020). Transition planning aims to establish shared goals and ensure that academic and functional skills are built in advance to prepare an individual for future educational opportunities (Cavendish et al., 2017; Millians, 2023). Key transition times include moving from elementary and middle school to secondary, post-secondary, vocational, or employment training. Transition planning can begin anytime, though earlier consideration can help support goal setting and intervention planning.

Educator & Caregiver Training

School professionals and caregivers can benefit from specific training regarding how FASD may impact behaviour and learning. Vital components of this training should include information about the range of brain-based and behavioural differences associated with prenatal alcohol exposure, the complexity of needs that require support in learning settings, and evidence-based interventions (Clark et al., 2014; Reid et al., 2020). Providing training to caregivers and educators can improve management of child behaviour and learning (Coles et al., 2015; Kable et al., 2007).



FASD-specific training may also increase caregivers' abilities to advocate for their children in education settings by increasing their understanding of their child's academic skills and improving their ability to communicate their child's needs to school staff (Millians, 2023).

The Canada FASD Research Network offers evidence-based, culturally sensitive training for professionals and caregivers of individuals with FASD:

<https://canfasd.ca/online-learners/>, which may help with providing practical knowledge and skills to enhance caregivers and other professionals' capacity to support healthy outcomes for individuals with FASD across the lifespan. There are different levels of training and opportunities available through this link.



Targeted Academic Interventions

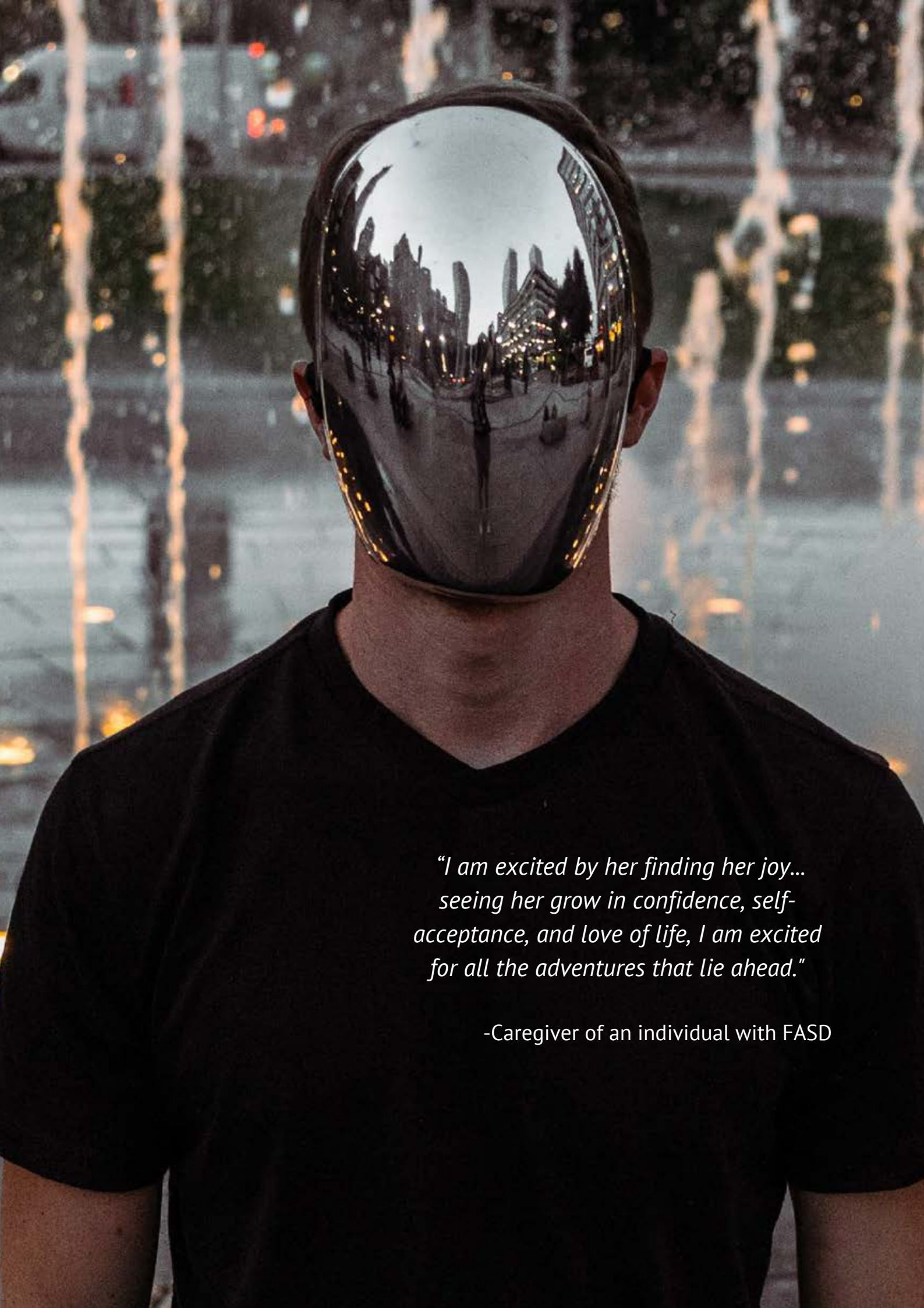
Mathematics is one core academic area in which children with FASD have notable difficulty (Rasmussen & Bisanz, 2009). Mathematics competency is essential for critical daily living adult functions such as money and time management, which may impact interdependence (Reyna et al., 2009; Ritchie & Bates, 2013). Early interventions that target foundational math abilities may be necessary for building skills that promote wellbeing in later life stages.

- **The Math Interactive Learning Experience (MILE)** uses metacognitive strategies and involves multisensory stimulation exercises to foster the development of mathematic skills (Coles et al., 2009; Kable et al., 2007). If adjusted for developmental level, these core intervention components within the MILE program can potentially improve basic math skills necessary for daily living across the lifespan (Kennedy et al., 2022).
- Interventions to improve early reading in children with prenatal alcohol exposure, such as the **Language and Literacy training program**, have been shown to improve letter knowledge, phonemic awareness, decoding, spelling, and object/category naming (Adnams et al., 2007).



Targeted Behavioural Interventions

Other intervention efforts have narrowed in on specific areas of behavioural functioning. For example, **GoFAR** has decreased disruptive behaviour and improved attention and adaptive skills in children with FASD (Kable et al., 2016). The program uses computer games, parent training, and therapy sessions with caregivers and their children to improve self-regulation and adaptive behaviours (Coles et al., 2015; Kable et al., 2016). A critical component of the program is using the **FAR strategy**, which, as previously described, stands for Focus and Plan, Act, and Reflect. By explicitly teaching children metacognitive strategies, like FAR, which encourages thinking about your thinking, they can learn to approach academic tasks or problems more thoughtfully rather than responding impulsively. This strategy has also been incorporated into targeted educational interventions, such as MILE, to support executive functioning and problem-solving approaches.



*"I am excited by her finding her joy...
seeing her grow in confidence, self-
acceptance, and love of life, I am excited
for all the adventures that lie ahead."*

-Caregiver of an individual with FASD

IDENTITY

The concept of identity can seem abstract and unclear, yet most people agree that it is a core element of healthy development. Identity refers to how we think of ourselves and who we think we are (Barry, 2022). Identity development occurs when we explore different interests, ideas, social environments, and knowledge (Kroger et al., 2010). In some ways, we can think of identity as a compass – by understanding who we are, we can begin planning a path forward. However, it is also so much more than this. Beyond who we are, the idea of identity is also often tied to how we feel about who we are. So, the question, ‘Who am I?’ is closely related to our sense of purpose and value. Consequently, identity development is crucial to our growth and evolution across the lifespan (Mousavi et al., 2019).

“If you really have your own identity, you’ll keep on doing what you think is really right for you, and you’ll also understand the next step you want to take.”

-Helmut Lang

Figure 1. Answering these questions can be a jumping-off point when exploring identity.



Our identity evolves across the lifespan. Adolescence is a period of notable identity development when we seek to distinguish our qualities, values, and interests from others. Many factors, including brain development, social expectations, and individual choices, are central to this period of growth and contribute to adolescence being an essential period of identity development. **Significant choices during this time can impact an individual's identity**, including:

- vocational and education **goals**;
- philosophical, moral, and spiritual/religious **choices**; and
- **self-expression** across various domains, including gender and sexual identities (Kroger et al., 2010).

Later in life, ***identity continues to evolve*** as we become adults, make new choices, achieve goals, and encounter novel situations.



FASD-Informed

Having an FASD diagnosis does not diminish identity's central role in a person's healthy development (Burles et al., 2018). The FASD community is increasingly contributing to research, underscoring the concept of “nothing about us without us.” However, we also hear that we need to understand better how healthy identity development may be supported for people with FASD (Burles et al., 2018). Existing research, albeit limited, points to relationships with others being important for people with FASD during their transition to adulthood as they navigate their burgeoning identity (Brenna et al., 2017; Burnside & Fuchs, 2013). Researchers have also begun to consider ways in which individuals with FASD may experience cultural, sexual and gender identity, as well as the impacts of stigma on identity.



This resource can help guide families to examine the impacts of FASD on how their child or early teen perceives themselves:

<https://fasd.me/wp-content/uploads/2023/07/My-brain-Me-and-FASD->

Culture

Culture is an essential aspect of a person's identity. Culture is the shared characteristics of a group of people that can encompass things like place of birth, religion, language, food, social behaviours and expectations, and art (Botha & Gillespie-Lynch, 2022). Culture is a set of norms and values that inform how we see the world. Multiple cultures can influence us because we can belong to different cultural groups. Sometimes, we may not notice these aspects of our identity when we have grown up in a place and with people who share them (Botha & Gillespie-Lynch, 2022). Connection with others is a significant area of strength for individuals with FASD (Flannigan et al., 2021), and helping people with FASD to form connections with their culture and heritage through their relationships may support identity exploration and encourage identity formation (Rogers et al., 2013).





“Culture and language have helped our son be successful. He is Indigenous, and having a strong Indigenous role model is key. That cultural connection will help break the cycle of FASD in his birth family.”

- Caregiver of an individual with FASD

Sexual & Gender Identity

Sexual and gender identity is a crucial component of adolescent identity development that informs how we behave, interact with others, and feel about ourselves (Schimmel-Bristow et al., 2018). In Canada, there have been significant shifts in societal understanding of sexuality and gender over the past ten years, including recognition of the environment and society's role in shaping a person's gender identity (Mousavi et al., 2019). Like other aspects of identity, sexual and gender identity development is not linear and can take several years to achieve (Schimmel-Bristow et al., 2018). Like FASD, sexual and gender identity is complex, and the combination of multiple sexual and gender identities with FASD can increase the challenges experienced by people with FASD (Dwomoh & Harding, 2023). Although there is currently limited research in the area of sexual and gender identity development among people with FASD (Dwomoh & Harding, 2023), research with people without FASD tells us that tools to support sexual and gender identity development may include positive peer and adult relationships, opportunities to explore, and acceptance from others (Schimmel-Bristow et al., 2018).

Stigma

Individuals with FASD may experience their identity reflected to them through the actions and words of others. This can be challenging for individuals with FASD, who often experience misunderstandings, stigma, and bias from others due to their diagnosis (Bell et al., 2016; Winsor, 2020). Interactions with others can impact the identity development of individuals with FASD through how they interpret the actions of others, and even well-intentioned actions can perpetuate stigma and create feelings of exclusion (Roozens et al., 2022). To avoid perpetuating stigma, caregivers, family members, and supportive others must **demonstrate hope and optimism** in their interactions with individuals with FASD (Poth et al., 2014). Supporting individuals with FASD to develop a positive identity in the face of such pervasive stigma requires acknowledging individual strengths alongside areas of need to support balanced and holistic identity development (Knorr & McIntyre, 2016; Petrenko & Kautz-Turnbull, 2018).

Moving Together

Identity Development in Childhood

Early identity foundations are laid in childhood and are formed through early experiences that provide examples of security, attachment, and competency (Prioste et al., 2020). For example, children's attachment experiences with their primary caregivers influence their perceptions of trust and security, which informs their relationships with others and how they perceive themselves (Tillman, 2016). Other experiences, such as physical development, relationships with family and peers, and environmental circumstances, can influence childhood identity (McAdams & Zapata-Gietl, 2015). In early childhood, children with FASD generally describe themselves using simple ideas tied to physical appearance. As children age, they typically begin to distinguish themselves from others using personality traits and eventually view themselves as unique, autonomous beings (McAdams & Zapata-Gietl tied to

To support the identity development of children with FASD, family members and trusted others can:

- **demonstrate** describing themselves and their child with FASD using developmentally appropriate language, such as outgoing, kind, or hard-working, and
- **provide** the child they support with opportunities to practice describing themselves and others using developmentally appropriate language.



For your consideration...

Identity is not one singular thing, but rather includes multiple aspects and areas of our development and daily functioning. Through the many stages of life, identity may shift and evolve but it is important to always respect each and every person's process as they navigate their own identity development journey. Autonomy, voice, and choice are essential considerations when supporting individuals with FASD to navigate their identity development. ***It is crucial that supportive others listen more than they talk.***

To action this, it is important to **listen** and **understand** each individual's priorities to provide holistic support and respectfully incorporate aspects of their identity into intervention planning.

Identity Development in Adolescence

Adolescence is a dynamic developmental period when we seek to answer the question 'Who am I?' Answering this question for adolescents and young adults with FASD is informed by their experiences and, in many instances, their FASD diagnosis (Burles et al., 2018; Erb, 2015). Adolescents with FASD have explained that the liberties afforded to their peers, such as visiting friends or family as they wish, were not afforded to them. They reported experiencing additional challenges related to identity development, including being a parent, completing their high school education, social skill development, and experimenting with drugs and alcohol (Burnside & Fuchs, 2013).

To help navigate these tensions, it is necessary to acknowledge:

- The potential differences that may exist in their cognitive strengths and needs and how they can inform identity development, exploration, and expression.
- That adolescents with FASD can benefit from individualized guidance from trusted peers and adults, including caregivers and support workers, during the transition to adulthood to support long-term planning and goal setting (Burles et al., 2018; Michaud, 2019).
- That adolescents with FASD often learn through observing and interacting with others (Branje et al., 2021). Modelling, such as describing how they identify, can be a practical approach to healthy identity exploration and achievement.




Identity Development Across the Lifespan

Significant transition points in adulthood can include entering middle age, becoming a parent, reaching retirement, and entering late adulthood. Through these and other significant changes, we engage in ongoing reflection and changing relationships with others that can provide opportunities for identity exploration.

As adults with FASD navigate their ever-evolving identity, researchers have noted:

- **Receiving an FASD diagnosis** can mark a significant turning point in self-perception for adults with FASD. The knowledge and insight provided by an FASD diagnosis can help to strengthen self-understanding, identity, and life purpose.
- **Helping adults with FASD to identify their strengths**, interests, and skills can not only improve their self-esteem and sense of competency but also help them understand and perceive themselves in a more holistic way (Brenna et al., 2017; Burles et al., 2018).



*“[I am excited] watching them
grow and continue to learn.
Seeing that they are moving
through challenges and coming
out the other side stronger.
Recognizing their resilience.”*

-Caregiver of an individual with FASD

INTERDEPENDENCE

People are better together. We do best in environments that are a good fit for us with people around us whose values, skills, and interests complement our own and whose expectations are realistic and tailored to our unique strengths and needs. Interdependence refers to how we engage with others and give and receive support (Columbus et al., 2021); it exists along a **spectrum** and fluctuates across situations, contexts, and development.

*“Independence is not realistic;
interdependence is.”*

- Caregiver of an individual with FASD



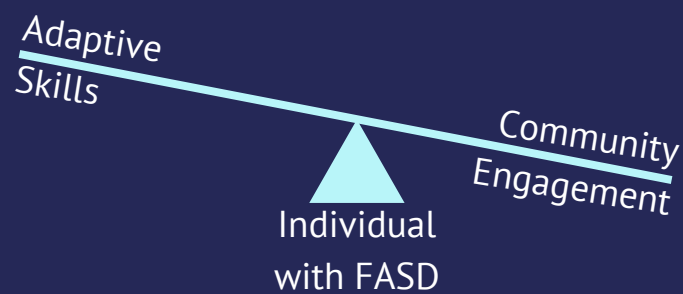
Interdependence reflects how our unique adaptive skills are balanced alongside our community engagement and support systems. Adaptive strengths and challenges vary from person to person and can be impacted by the task, setting, and expectations. Alongside these skills, we also encounter a wide range of systems and environments throughout our lives, each with its own set of expectations that vary across ages, relationships, communities, contexts, and cultures. A balance between a person's adaptive skills and community engagement informs their level of interdependence, as shown in Figure 1.

Did You Know?

Our level of interdependence *fluctuates* across the lifespan! Each person's adaptive skills and community involvement look different as children, teens, and adults.



Figure 1. *Achieving Interdependence Requires Balance*



We must center the individual when considering the level of supports required and what interventions are most appropriate to support interdependence. Interdependence occurs when we find a balance between adaptive skills and community engagement. The level of community engagement required varies depending on the individual's unique areas of strength and need. Providing opportunities for community engagement and support, alongside leveraging the individual's adaptive strengths and engaging in adaptive skill building where needed, leads to a balance that meets the individual's unique needs. For some people, interdependence looks like getting eyeglasses from the optometrist or food delivered from a grocery store. For others, it looks like help with daily chores or decision-making. Because community engagement is so integral to the interdependence balance, ***it is crucial that supports are maintained***, not removed, when success is achieved.

Adaptive Skills.

Adaptive functioning includes our abilities related to self-care, social interactions, and functioning within the broader community (Crawford et al., 2020). Adaptive functioning is based on developmental, social, and cultural standards for personal autonomy and social responsibility (Mash & Wolfe, 2018). Adaptive skills include:

- **Conceptual** skills: reading, writing, and math.
- **Social** skills: communication behaviours, capacity for relationship development, and understanding social cues.
- **Practical** skills: grooming, dressing, hygiene, and eating.

Adaptive skills vary across developmental levels, from person to person, and may be stronger in some areas than others based on our experiences, age, ability, and opportunity (Mash & Wolfe, 2018). Identifying an individual's unique areas of strength and need can help to inform potential areas for intervention and adaptive skill building.





Community Engagement.

Community engagement refers to our sense of belonging in our community. It involves having activities to stay busy, a social network, access to medical and social services, and a sense of autonomy (Clark et al., 2008; Simplican et al., 2015). Our sense of self-determination, social identity, reciprocity and contribution, and psychological safety also contribute to our sense of community belonging (Milner & Kelly, 2009). Community engagement is enhanced by reciprocal relationships with family and friends who share common interests (Cummins & Lau, 2003; Simplican et al., 2015). Active engagement in community activities can boost self-esteem, confidence, and feelings of empowerment (Marshall et al., 2020). People actively involved in their community have also reported improved fitness and nutrition, increased happiness, and less loneliness, depression, or anxiety (Attree et al., 2011; Simplican et al., 2015).



For your consideration...

There are many practical applications to using interdependence as a framework for finding a balance between a person's unique adaptive skills and their community engagement. Consider, for example, a 12-year-old boy named "Johnny" who plays on a school basketball team. Johnny is good at running and cheering on his teammates during games. He is described as a good sport who is motivated to help his team win. Johnny's coach has noticed that Johnny needs reminders about when to stop talking so that his teammates can focus during the game, and to keep his language appropriate when talking to the opposing teams. Through consistent support and engagement from Johnny's coach and teammates, including reminders and verbal prompts, alongside opportunities for ongoing development of Johnny's adaptive skills, Johnny has been able to experience success on his basketball team.



For Johnny and other people with FASD, adaptive skills and community engagement are going to continue evolving throughout their lifespan. The adaptive skills and community engagement required at 6, 12, 18, 24, 30, 35 years old, and beyond are going to be different. To support healthy outcomes, ongoing evaluation and re-adapting supports as needed are crucial.

FASD-Informed

Interdependence is a “two-way street”; support is both given and received. Many people with FASD want to contribute and have a role in their community (Kapasi et al., 2019), which can foster meaning and a sense of personal value. Opportunities to give back to the community for people with FASD can vary depending on the individual’s strengths and interests, their relationship with others, and the community’s needs. **Examples include:**

- Spaces where individuals with FASD can **voice their opinions**, perspectives, and preferences and where these preferences are valued and considered when making decisions (Michaud, 2019),
- Team sports or related activities wherein individuals with FASD can **leverage existing abilities and strengths** within a team environment that understands their areas of need and supports their growth,
- Volunteer positions where people with FASD can **share their time and skills** with others,
- Community events and activities, such as cultural days or fundraisers, that individuals with FASD can attend or **help organize**, and
- Employment or vocational environments **tailored to meet the needs** of individuals with FASD while simultaneously building on their strengths (Kapasi et al., 2019).



For your consideration...

As disability policies have shifted focus, community participation is increasingly considered an essential dimension of human functioning (Verdonschot et al., 2009b). Providing opportunities for individuals with disabilities, including those with FASD, to make choices, be involved in policy development, reside in small residential facilities, and participate in vocational services all positively impact community participation and support autonomy and interdependence for individuals with disabilities (Verdonschot et al., 2009a).

Developmental Transitions

From early childhood through adolescence and later adulthood, we grow and develop in ways that change how we interact with our community. Some of these changes reflect brain-based developments, and some of them reflect our environment as our support systems and broader community evolve, and we are granted greater autonomy. Such transitions highlight the dynamic and reciprocal nature of interdependence. For example, shifting from the classroom to job sites in early adulthood requires big leaps in skills and self-management abilities. Life transitions can create tensions for individuals with FASD seeking to develop their autonomy while navigating increasingly complex, unstructured, and unfamiliar environments (Burnside & Fuchs, 2013). When skill development does not match changes in the level and types of support a person receives, we set people up for failure.



Resources for Caregivers looking to support individuals with FASD through periods of transition are here:

- A **review of transition planning tools** for youth with FASD: <https://canfasd.ca/wp-content/uploads/publications/41026-JoDD-24-1-v11f-81-98-Coons-Harding-et-al.pdf> and a **corresponding infographic** that summarizes the review: <https://canfasd.ca/wp-content/uploads/2019/11/Transition-Planning-for-Individuals-with-FASD-Infographic.pdf>
- A **webinar presentation** summarizing transition planning with youth with FASD: <https://www.youtube.com/watch?v=4w68wAEYyms>
- A **toolkit for caregivers and individuals with FASD** to help support transition planning for adolescents and young adults with FASD: <https://lcfasd.com/wp-content/uploads/2017/09/Transitioning-Youth-to-Adulthood-Final-REport-2.pdf>

Environmental Influences

When fostering interdependence for individuals with FASD, supportive others should reflect on how we understand the underlying function of the behaviours and choices of people with FASD. In so doing, it is essential to consider the impacts of environmental factors:

- **Personal growth** for people with FASD can be promoted in an environment that sets developmentally appropriate expectations for interdependence and provides individualized support alongside scaffolded learning opportunities.
- Opportunities to **observe and practice** skills are necessary to foster the adaptive functioning of individuals with FASD across the lifespan.
- Supporting individuals to practice adaptive skills using **relational, applied, hands-on tasks and community-based experiences** can build on existing strengths and promote learning and development.

Unique Brain

Brain-based differences associated with prenatal alcohol exposure can directly impact behaviour by affecting the development of adaptive skills (Jirikowic et al., 2008; Lynch et al., 2015), making it harder for individuals with FASD to apply these skills in their daily functioning (Doyle et al., 2019). An individual may “know” how to complete a task but then struggle to *apply* that knowledge consistently. This can lead to difficulties with accessing higher-level skills known as executive functioning, such as inhibition, working memory, organization, and communication, and can impact how people respond to dynamic social and environmental interactions (Crawford et al., 2020). Increasing stress levels can also add to frustration with meeting daily expectations, magnify difficulty accessing skills, and increase avoidant behaviours among individuals with FASD.

Moving Together

Setting Goals

Normalizing and prioritizing interdependence requires appropriate expectations and goals for people with FASD (Michaud, 2019). This can look like adjusting expectations around timelines for achieving developmental milestones, such as obtaining a driver's license, moving away from home, or seeking employment, and developing strong bonds between individuals with FASD and their family members. Strong relationships with supportive family members can create mutual reliance and skill development that support interdependence. Creating specific roles at home, school, and in the community with scaffolded skill development for individuals with FASD where others rely on them (e.g., cleaning, cooking, and errands) can foster reciprocity and interdependence.



Skill Building

With appropriate intervention and support, the adaptive skills of individuals with FASD can be improved (Ase et al., 2012). Adaptive skills are easily modelled, rehearsed, and reinforced and can make experiential learning fun! **Adaptive skills can be targeted through:**

- A **computer-based intervention** used to support critical learning related to fire and street safety skills for kids with FASD (Coles et al., 2007). Game components included settings that mirrored the child's environment, praise when the child chose safe behaviours, and explanations when the child chose unsafe behaviours, such as crossing the street without looking both ways. Opportunities to practice safety behaviours in a setting like their home and school environments helped children with FASD learn essential safety skills and fostered adaptive functioning.
- Mentorship programs like the **Wellness, Resilience, and Partnership (WRaP)** program can promote day-to-day success and wellbeing for individuals with FASD. WRaP mentors work one-on-one with individuals with FASD to guide and empower them through vocational, educational, and community support to help them be more involved in their community. WRaP mentors help parents connect with community programs, access resources, and educate community service providers about FASD and how to adapt support and interventions for people with FASD (Harding & Flannigan, 2020). WRaP highlights genuine, safe, and compassionate relationships to facilitate the growth and development of adaptive skills (Harding & Flannigan, 2020; WRaP, n.d.).



Tailoring Environments

Across the lifespan, the intersection between community engagement and interdependence can be optimized by **proactively and intentionally creating a well-suited environment** with room for growth and flexibility. “Well-suited” environments often include structures and supports to scaffold learning and appropriate expectations for the individual, which can support the growth and development of people with FASD. Creating an environment uniquely suited to someone with FASD requires proactive maintenance of structures and supports based on an understanding of brain-based differences and environmental adaptations tailored to the unique strengths and needs of each person with FASD. Individuals with FASD can benefit from explicit support and structure to learn adaptive skills such as reminders, explicit cues, communication aids, lists, and repetition.

Finding Your Village

Caregivers are integral to supporting the interdependence of individuals with FASD (Clark et al., 2008), and caregivers should not stand alone. Together, we can build networks of support that include close family and friends who can facilitate trusting relationships between individuals with FASD and the broader community. Potential **strategies to support the wellbeing of caregivers** of individuals with FASD can range from support groups, a consistent self-care routine, therapy or counselling supports, and respite services.

Community engagement for people with FASD may be supported by:

- **Considering** the interests, feasibility, and potential challenges that individuals with FASD may experience as part of making supported choices (Michaud, 2019),
- **Establishing** places in the community where individuals with FASD feel known and can establish positive self-identities (Gibbs, 2019),
- **Emphasizing** opportunities for individuals with FASD to engage in reciprocal community contribution to challenge implied dependence (Kautz et al., 2020), and
- **Seeking** opportunities where individuals with FASD can be challenged and achieve well-suited expectations (Michaud, 2019).

EMPLOYMENT

Employment is often an integral part of adult life and provides people with a sense of purpose and meaning. People usually seek employment that suits their unique skills and interests and provides a competitive wage, fair working hours, and opportunities for professional growth. Successful employment requires balancing the person's unique strengths and needs and the employment environment. Supported employment is an evidence-based, individualized, and strength-based approach to finding a balanced fit between the individual and their employment environment to maximize their opportunities for successful employment (Green, 2016). **Supported employment environments** are more likely to lead to sustained and enjoyable employment experiences.



FASD-Informed

Individuals with FASD have many abilities that can support their successful employment. Support from their environment and community is often required to achieve their employment goals, and many individuals with FASD have reported long-term employment success when given appropriate support (Kapasi et al., 2019; Nagy et al., 2019).

Unfortunately, there are limited integrated employment opportunities for individuals with FASD due to a lack of information and potential stigma related to FASD (Moll et al., 2003; Green, 2016). Understanding FASD, the unique strengths and needs of the individual, and the employment environment are all necessary considerations when preparing for, obtaining, and maintaining successful employment.

Identifying Supports

To understand the type of employment supports a person with FASD would benefit from, it is essential first to understand how their **unique brain and environmental experiences may impact their functioning**:



- Individuals with FASD may experience challenges related to stamina, timeliness, flexibility, and adaptability, thus may need help staying focused, adhering to timelines, and adapting to changes (Culbertson et al., 2013).
- People with FASD have also demonstrated many **areas of strength** related to employment, including persistence, non-judgmental attitudes, and compassion for others (Community Living British Columbia, 2011; Flannigan et al., 2021). Such traits are essential skills that employers often seek.
- Individuals with FASD also demonstrate an interest in others and **strong relational skills**. Mentorship, guidance, and tactile learning opportunities can further their learning and employment-related skill development.
- Volunteerism should not be overlooked as an opportunity to **experience meaning** and contribute to society. Volunteering can also provide the chance to try a career or experience a workplace before obtaining paid employment.

For your consideration...

An individual with FASD tasked with organizing work materials might begin to feel overwhelmed and bored, and instead, they spend much of their day chatting with co-workers. They might appear distracted to others, but *underlying* these behaviours is an attempt to regulate their feelings.



Employment Success

The employment experiences of individuals with FASD are more likely to be successful when other parts of a person's basic needs, such as housing and mental wellness, are also consistent and well-supported and when in an environment well-suited to their unique areas of strength that provide appropriate support to address areas of need (Kapasi et al., 2018). Successfully held employment can lead to feelings of pride and accomplishment for individuals with FASD (Temple et al., 2021), and offers them a chance to contribute to their communities and develop a sense of meaning in their lives.

“She is responding to talk therapy and looking towards the future at higher education and vocational training possibilities. Her job is going well.”

- Caregiver of an individual with FASD



Moving Together

Workplace Environment

Individuals with FASD, their employer and colleagues can work together within the employment environment to identify and apply different strategies and accommodations to support employment success (Community Living British Columbia, 2011). **Helpful strategies may include:**

- repeated instructions,
- extra opportunities to practice,
- verbal and written instructions, and
- reminders.

Potential workplace **accommodations** include:

- delineated roles,
- routines and consistency,
- clear communication, and
- repeated training opportunities as needed.

Employee Satisfaction

When people feel that they are contributing to their workplace meaningfully and have healthy relationships with their colleagues and supervisors, they are more likely to enjoy their jobs (Community Living British Columbia, 2011). Employment satisfaction is related to the relationships employees have with others in the workplace, employee engagement, and the type of support provided (Raziq & Maulabakhsh, 2015). Individuals with FASD often demonstrate strong motivation around interpersonal relationships and often seek close relationships with others (Flannigan et al., 2021). Employment environments that offer opportunities for reciprocal social relationships can be critical to the employment success of individuals with FASD.

Planning Ahead

The Canada FASD Research Network created a guide to support the employment journeys of individuals with FASD, including preparing for, obtaining, and maintaining successful employment for support service providers and employment professionals: canfasd.ca/employment.



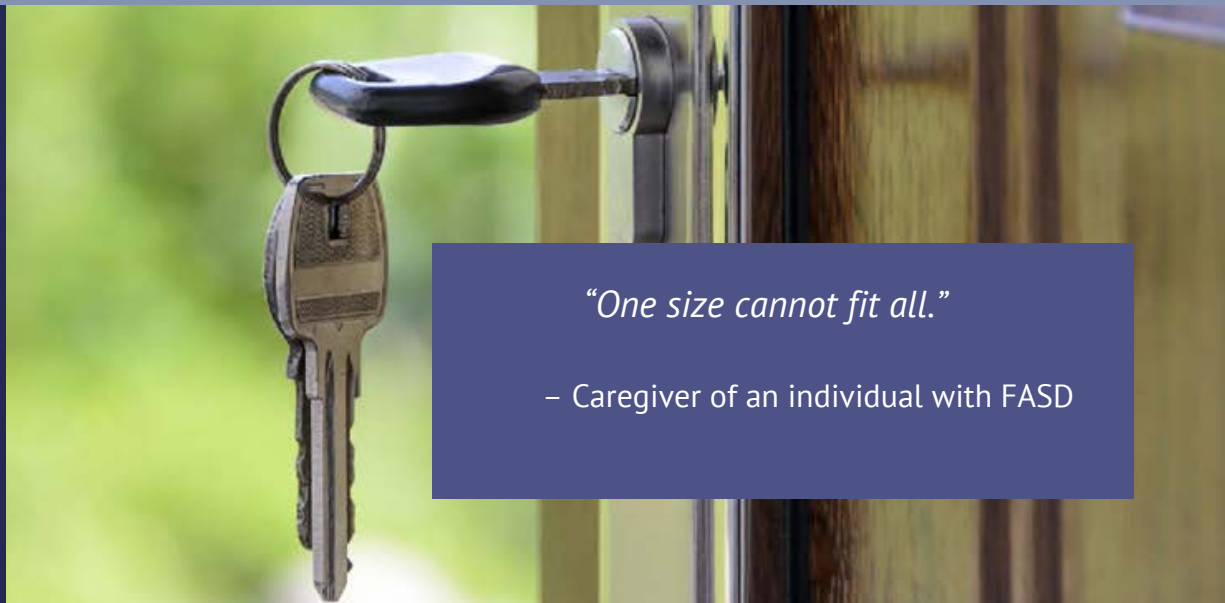
HOUSING

Access to safe, affordable, and secure housing is a *fundamental human right*. Having stable housing means a person can access living situations that support an optimal quality of life and wellbeing (Sylvestre et al., 2009). Housing is an essential basic need, and its long-term maintenance is necessary for supporting a person's physical wellbeing and mental health (Rolfe et al., 2020). Housing stability can also affect relationships, employment, and community engagement. When basic needs like stable housing are unmet, we struggle to meet more complex and higher-level needs, such as maintaining healthy relationships and attaining personal goals. **Meeting the basic physiological need for shelter is part of an essential foundation** for developing relationships and acquiring new life skills.



FASD-Informed

There is limited consensus regarding the housing needs of people with FASD (Pei et al., 2018). However, based on several studies and conversations with frontline workers, individuals with FASD can successfully maintain long-term housing with **ongoing, individualized support** (Pei et al., 2018). Understanding the unique strengths and needs of the individual in need of support is central to building respectful, goal-oriented relationships between the service provider, caregiver, and the individual with FASD to provide safe, secure, and stable housing.



“One size cannot fit all.”

– Caregiver of an individual with FASD

Establishing Shared Understanding

When housing frontline workers, landlords, and other supporters are equipped with information that facilitates understanding, service providers can respond proactively to FASD-related challenges (Joly et al., 2022). For example, an individual with FASD who needs help understanding the language in a lease agreement would benefit from support when reviewing the agreement to make sure the information is understood.

Future Consideration

Watch for upcoming research on housing and FASD in the near future from the Canada FASD Research Network!



Adapting Supports

Brain-based differences can impact how individuals with FASD learn and practice the adaptive skills needed for maintaining housing (Brownstone, 2005). Difficulties navigating new routines and social environments may impact the support needed daily. For example, an individual with FASD may require support interacting with new neighbours, finding the mailbox, and completing maintenance tasks such as shoveling snow. Service providers must adapt expectations and set developmentally appropriate goals to suit the unique strengths and needs of each person with FASD, which may include working towards completing household tasks with appropriate levels of support and developing strategies to support daily living skills.

People with FASD may experience difficulties with executive functioning and related skills, including organization, planning, communication, and memory, which can impact their ability to manage housing. However, individuals with FASD often have strong interpersonal skills, such as being outgoing, friendly, and motivated to work as a team (Flannigan et al., 2021). These characteristics are vital for positive engagement in programs focused on teaching and practicing living skills that support housing maintenance (Denys et al., 2011).



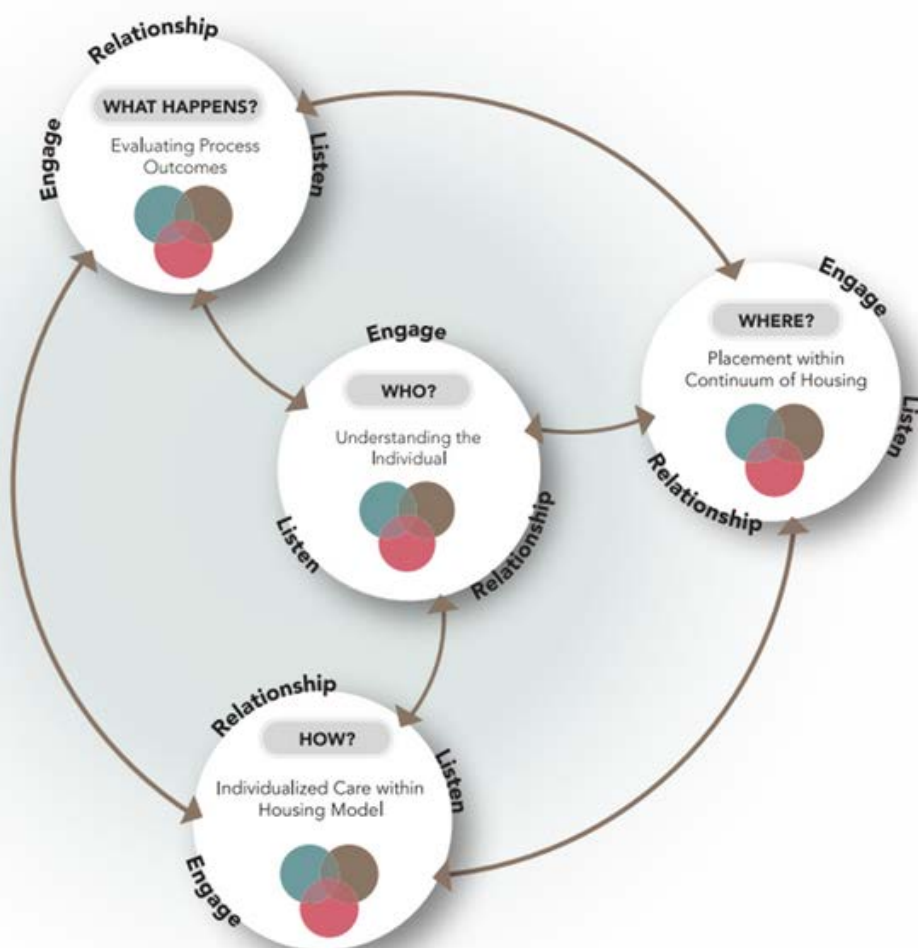
Moving Together

Housing First

Housing First programs are based on the understanding that individuals must have permanent housing before navigating other related challenges, and aimed to support individuals unable to participate in traditional housing programs (Aubry et al., 2015). Housing First clients are provided support to find and access immediate, permanent housing based on market availability. Housing First programs emphasize choice, including the location, housing type, and participation in treatment or community programs (Aubry et al., 2015). A Canadian study of Housing First found that after 12 months, 73% of Housing First participants remained stable in their housing context, compared to 31% of traditional program participants (Aubry et al., 2015).

Although there is little research related to housing individuals with FASD (Woodhall-Melnik & Dunn, 2016), it holds promise for individuals with FASD. Engaging in conversation with individuals with FASD and their support team in proactive and responsive ways may help leverage the tenets of the Housing First approach and help ensure appropriate expectations and supports are in place.

Figure 1. *Person-Centred Framework for Housing People with FASD*





Planning Ahead

The Canada FASD Research Network, in partnership with the University of Alberta, created **a systematic and person-centred framework for supporting housing** workers, caregivers, and supportive others walking alongside individuals with FASD in their housing journey (Figure 1): <https://canfasd.ca/topics/Housing-Homelessness/>



Housing Design Principles

Proof Alliance (2021) developed a guide for improving the function of new or existing housing to support better the strengths and needs of young adults with FASD. They identified eight design principles and strategies to incorporate in homes, such as location, security, and layout.

Location

Housing near accessible transit systems and essential services like grocery stores can make it easier for individuals with FASD to participate in regular routines and practice daily living skills.

Security

As individuals with FASD can be ~~more~~ vulnerable to manipulation, the safety of the building and the area surrounding it should be considered. The safety of the community impacts potential social engagement and day-to-day routines.

Layout

Décor choices, material selection, and the floor plan can support executive functioning and mental wellbeing. Having an organized space that is easy to navigate can support individuals with FASD who have brain-based differences to thrive in their living space, which allows for personalization, privacy, and easy maintenance.

Other factors, including colour, organization, and natural elements, can also be used to create a positive home environment:

Colour

choices can impact our mood and physical wellbeing (Aijilian et al., 2014). Cool colours, such as blues or greys, can help us feel more relaxed.

Organization

and layout choices can be used to help with daily functioning. Ensuring items are clearly visible will make it less like that they will be forgotten.

Nature

like indoor plants, can help us feel more comfortable in our living space. Connections to nature can be helpful for regulation.

PARENTING WITH FASD

Parenting involves raising, promoting, and supporting a child's physical, social, emotional, and cognitive development into adulthood and, in many cases, this support can continue through much of adulthood. Parents play a significant role in the development of their children and can help set them along a pathway to healthy outcomes. The role of a parent is often demanding, as children require constant care, support, and nurturance. As children develop and grow, so do their needs, and parents must often adjust their expectations and actions accordingly. Like their children, the strengths and needs of parents are dynamic and constantly evolving. Many parents require support to foster their caregiving skills as the needs of their children develop, and targeted interventions can significantly improve parent skills and the wellbeing of their children (Jeong et al., 2021). Providing parents with support, education, and strategies will allow them to meet the ever-evolving needs of their children and themselves across the lifespan. In many cases, raising children and providing support into adulthood are best done within a community and in relationships with trusted others. As it is commonly said, raising a child takes a village! Identifying areas where parents with FASD require support and leveraging strengths is an essential early step to developing parenting skills and building a village of support.



FASD Informed: *I am a parent, and I have FASD*

People with FASD often want to start a family and have children of their own (Denys et al., 2011; Grant et al., 1997). At present, it is largely unknown how many individuals with FASD have children and are currently parenting, though earlier work showed that 28% of females and 10% of males with FASD in the United States over 12 years old had one or more children (Streisguth et al., 1996). Parenting requires many skills, including problem-solving, empathy, patience, stress management, communication, flexibility, autonomy, and adaptability, which are areas where individuals with FASD may struggle. Many individuals with FASD have also been exposed to adversity, including disrupted attachment experiences. The interaction between brain-based differences and adversity may impact how individuals with FASD access and apply skills necessary for parenting (Harding et al., 2020).

The relationship between cognitive functioning and parenting capacity is complex and likely impacted by many factors, including environment, community integration, and resource access (Abraham, 2005; Slayter & Jensen, 2019). However, with the proper support and accommodations, individuals with FASD can build on their existing parenting strengths and expand their skills (Rutman & Van Bibber, 2011). Helping parents with FASD to develop strong skills and build a community allows for opportunities to support healthy outcomes across the lifespan for parents and their children.

“They are amazing parents, because they take what they struggled with and make it not an issue with their children.”

- Caregiver of an individual with FASD



Parenting Challenges

Parents with FASD have attributed some of their parenting challenges to their disability, including difficulties with memory, organization, and integrating sensory cues (Rutman & Van Bibber, 2010). The most commonly reported barriers for parents with FASD include a lack of FASD training for caseworkers and limited resources, time, and funding (Abraham, 2005). Some parents with FASD need help managing daily parenting tasks, such as appointment reminders, transportation access, and parenting support groups. Parents with FASD have also stressed the need for parenting materials that are clear and understandable for those with FASD (Abraham, 2005).

Additionally, people with FASD have described barriers in their role as parents stemming from negative societal attitudes towards FASD, which can impact their parental status (Rutman & Van Bibber, 2010). These attitudes can cause individuals with FASD to feel that their parenting abilities are under scrutiny which can create anxiety and feelings of inadequacy around parenting (Rutman & Van Bibber, 2010). As a result, parents with FASD do not always feel included in decision-making processes and are not encouraged to share their opinions when intervention planning and goal-setting.



Parenting Successes

With appropriate support, guidance, and access to the necessary resources, individuals with FASD can engage in meaningful parenting and develop skills to respond to challenges that can arise in their role as parents. Parents with FASD who have experienced success reported using multiple **strategies to meet their parenting goals** throughout daily life, including:

- regular use of **calendars**,
- highly detailed **instructions**,
- written **schedules**,
- ‘**self-talk**’, such as talking through steps in their minds,
- consistent **routines**,
- regular **boundary-setting**,
- focus on their **children's strengths** and characteristics, and
- taking **time outs** for their own regulation (Rutman & Van Bibber, 2010).

Moving Together

Recognizing Patterns & Breaking the Cycle

When supporting people with FASD as parents, it is essential to consider their unique needs and the impacts of early relationships and environments later in life. For parents who experience childhood adversity, they may prioritize moving beyond adversity and “breaking the cycle,” the meaning of which varies. For some parents, this may mean breaking the cycle of abuse in their families, whereas for others, it may mean breaking addiction patterns. **All parents want to create a better environment for their children than they had experienced as a child** (Grant et al., 2004; Rutman & Van Bibber, 2011). It is essential that support workers and trusted others understand the parenting goals of individuals with FASD and walk alongside them to achieve parenting success and healthy outcomes.



Leveraging Relational Strengths

Catholic Social Services in Edmonton, Alberta, offers mentorship to parents with FASD for three years beginning in pregnancy (Denys et al., 2011). Parents who participated in this program have experienced improved parenting skills, along with improved abilities to meet their own needs. Mentors of this program shared that although advocacy and support provision specific to parenting is essential, much of a client's success depends on stability across many domains of life, particularly in having consistent access to basic shelter, safety, and food (Denys et al., 2011). **Essential components of mentorship include:**

- securing and strengthening **connections** and integration within clients' local communities,
- access to **income** and employment supports,
- access to **affordable**, stable housing,
- referral of family members for neuropsychological **assessments** as needed, and
- access to addiction **services**, crisis management, and recreation resources (Denys et al., 2011).

The **Parent-Child Assistance Program (PCAP)** is another mentorship-based program developed to support women at risk of having a child with FASD (Grant et al., 2004), and has also supported women with FASD who are parenting. PCAP assigns case managers to families for three years, beginning during pregnancy. It has helped mothers reduce their use of alcohol or drugs and has led to increased housing stability (Grant et al., 2004). Case managers and critical community service providers engage in training regarding the potential impacts of FASD, the underlying causes of behaviour, and diagnostic processes. Case managers then work to support parents with FASD to increase their ability to access support and improve the quality of services available to parents with FASD in the community.

Case managers provided parents with:

- **positive** and **empathetic** relationships,
- **assistance** with problem-solving, and
- **referrals** to community services.

Mentoring programs can provide a relational and proactive approach to supporting parents with FASD in meeting basic stability needs and accessing the resources that may help them engage in consistent parenting strategies and build additional support networks. This may, in turn, help parents to “break the cycle” and create healthier developmental pathways for themselves and their children.



For your consideration...

Sometimes, caregivers are unexpectedly involved in raising their grandchildren and great-grandchildren. Services and policies that seek to support individuals and families with FASD should create space to consider and respond to the needs of *all* types of caregivers.



Conclusion

“Having no expectations shows pity, which shows sadness, sorrow & regret. A child with a disability needs support. Stand behind him, champion and back him! Believe in him and have expectations! [Expectations] inspire hope, excitement, eagerness and success! Which would you want others to give you?”

- Joan Scanlon-Dise



Individuals with disabilities, including those with FASD, seek purpose and meaning to live a healthy and fulfilling life. By creating opportunities for meaningful success experiences through intervention approaches, individuals with disabilities can move towards healthy outcomes. The revision of the Towards Healthy Outcomes Framework is important to continue to facilitate a shared understanding of intervention goals, increase consistency and intentionality, establish shared language, reflect a shared philosophy, and begin a conversation. Towards Healthy Outcomes Framework 2.0 will hopefully continue to have widespread use for researchers, policy makers, professionals, family members, supporters, and individuals with FASD.



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