

TOWARDS HEALTHY OUTCOMES FOR INDIVIDUALS WITH FASD

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SUGGESTED CITATION

Pei, J., Kapasi, A., Kennedy, K.E., & Joly, V. (2019). Towards Healthy Outcomes for Individuals with Fetal Alcohol Spectrum Disorder. Canada FASD Research Network in collaboration with the University of Alberta.



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TOWARDS HEALTHY OUTCOMES

All human beings are motivated to experience purpose and success. It is not enough to ‘get by’ in life, rather we must feel as though we are achieving expectations set by us and others. People of all abilities need to feel as though they have a purpose and that they are able to meaningfully contribute to society.

However, the pathway to these experiences may be unique and not necessarily in line with systematic approaches to nurturing success. 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 just stupid.”

With complex populations, such as those with Fetal Alcohol Spectrum Disorder (FASD), wherein the nature of the lifelong disability may be different for each individual, finding this pathway can be even more difficult.

Moreover, a lack of understanding may present an even greater challenge. But, with a shared roadmap we might gradually work towards improving our approach to finding that pathway and supporting forward movement that is the right fit for each individual.

By implementing interventions and/or supports we create opportunities for targeted skill growth and development, while also shifting environmental supports and expectations in order to optimize opportunity. The goal is to promote well-being and generate opportunities for meaningful success. Broadly speaking, we use the language of “intervention approaches” to capture both the targeted and supported aspects of intervention. In our quest for healthy outcomes, researchers, community members, and families have reminded us that meaningful outcomes arise from meaningful understandings.



Taking this perspective steers us towards the question, “what do I know”, instead of “what do I do”. From this perspective we can:

1) Build on existing strengths and address areas of challenge in order to help move towards healthy outcomes. Healthy outcomes emphasize healthy living and quality of life, not solely remediation of deficits.

2) Ensure interventions are implemented appropriately, in a timely and proactive manner, and be tailored to the individual and their community.

3) Engage communities and individuals with FASD in developing intervention approaches that are meaningful and feasible.

To help support intervention approaches across the lifespan, the Healthy Outcomes model has been developed to help support intervention approaches across the lifespan. This model embodies this perspective, and provides us with a roadmap that can help to think carefully and proactively about healthy pathways.

The model is founded on core beliefs that reflect integration of the research with wisdom from communities and caregivers, as well as the lived experiences of those with FASD.

**“I am neither an optimist nor pessimist, but a possibilist.” -
Max Lerner**

CORE BELIEFS

The need for understanding is central to this model. As our understanding grows, we position ourselves for more appropriate and compassionate intervention approaches. Yet, to support intervention approaches, understanding must be more than a word or a sentiment. Thus, we situate ‘understanding’ within the expression that all behaviour is functional. From this premise we are then tasked with determining what the utility of an observed behaviour may be. By working together, we may increase our understanding of the goals met through behaviours and consequently identify alternative approaches to goal pursuit that may also align with broader community or system level goals. For example, movement around the classroom might be a child’s attempt to resolve tension in their legs. By understanding the function of the behaviour we are able to find appropriate alternative solutions for this child that align with the goals of learning in the classroom. Needs vary as much as individuals with FASD vary, and thus it is vital that we spend time and effort to get to know the individual with FASD before implementing and evaluating strategies.

In pursuit of understanding, this intervention model is aligned with three core tenets: 1) a developmental lifespan perspective is necessary at all ages and stages, 2) interactive systems have additive and ongoing influences, and 3) our approaches must always be strength based, empowered, and goal oriented. These core tenets guide the design and implementation of the model (see figure 1).

1) By adopting a developmental lifespan perspective we acknowledge that an individual grows and changes over time, both in terms of their capacities as well as their goals. In any given moment we exist within present developmental capacities, while we are influenced by our past, and looking into our future. In this same way intervention approaches need to reflect unique developmental capacities, with knowledge of how those capacities have been, and continue to be, influenced by experiences and figure into shaping of goals and actions. As represented by the figures in the middle of the model, not only do we move through developmental stages as we grow, but we remain influenced by the past while also looking towards the future. This implies that we need to be considering “what we know” from a holistic perspective of the person across time.

2) As individuals with FASD grow and develop through their lifespan, they often interact with multiple systems, whose influence is additive and interactive. This implies that domains of support, externally defined, must interact fluidly and flexibly in response to individual needs at different times throughout the lifespan. Children and families frequently receive support from many sources and collaboration, communication, and cooperation are essential in order to best support individuals with FASD. In addition, communication is critical for system navigation. This requires meaningful collaboration and responsivity between service providers and individuals with FASD and their families. The layers of colours in the model represent the cumulative impact and influence that the domains have on each other.

3) This model is strength-based and empowered. Every individual with FASD has resources, assets, and strengths. Within each domain there are both strengths and weaknesses that may be identified, supported, and/or mitigated. Intervention approaches are not only beneficial to assuage challenge, but also to promote and capitalize on strengths. It is critical that we build on what is already successfully known and used, and support learning through these strengths. A strength-based and empowered approach vests power in the individuals with FASD and their families, and casts service providers as partners (Laursen, 2000). It is the combination of individual strength and engagement, along with meaningful involvement of supports systems that creates conditions for success. Success is co-created as we walk with, not for, individuals with FASD. Individuals and families have the right to participate in decisions about their current situations and their futures. This model 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 supports.

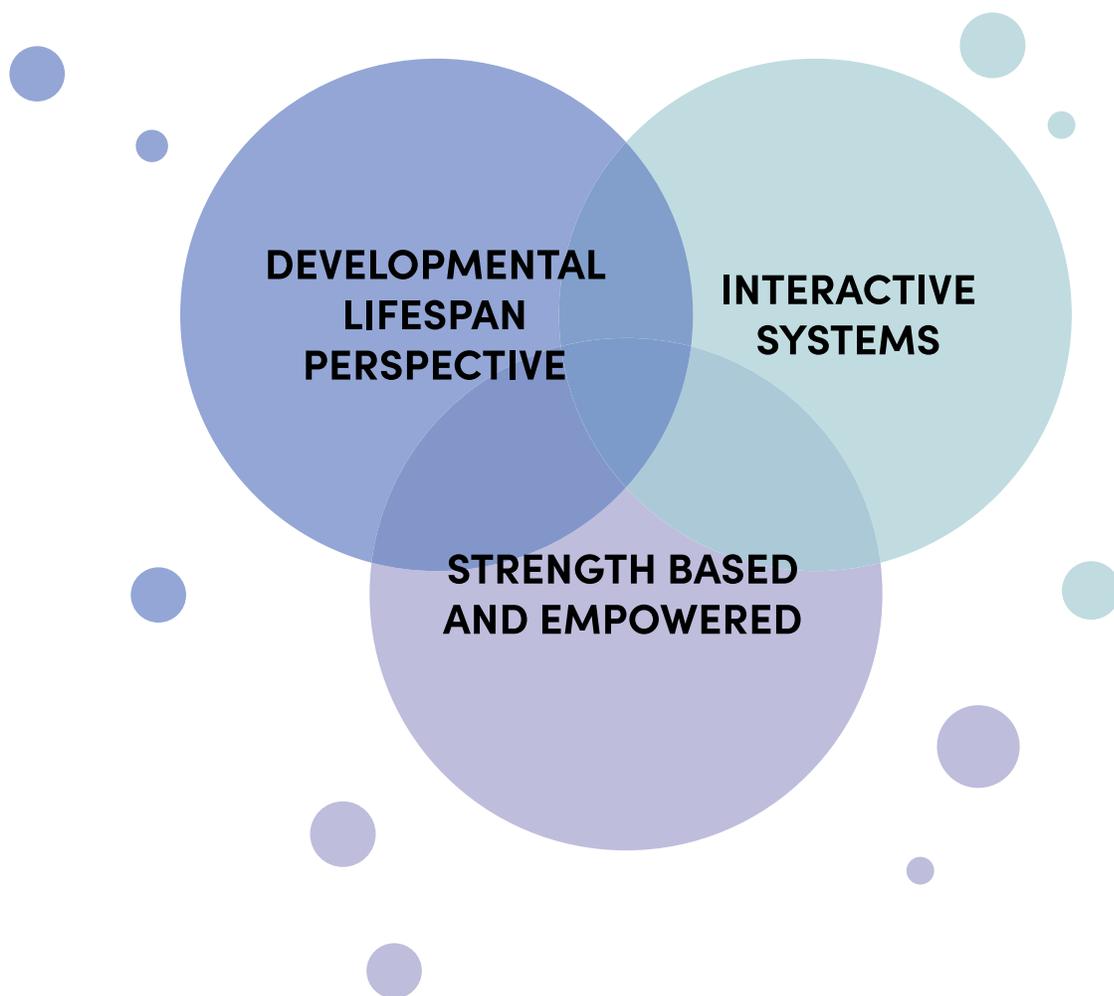
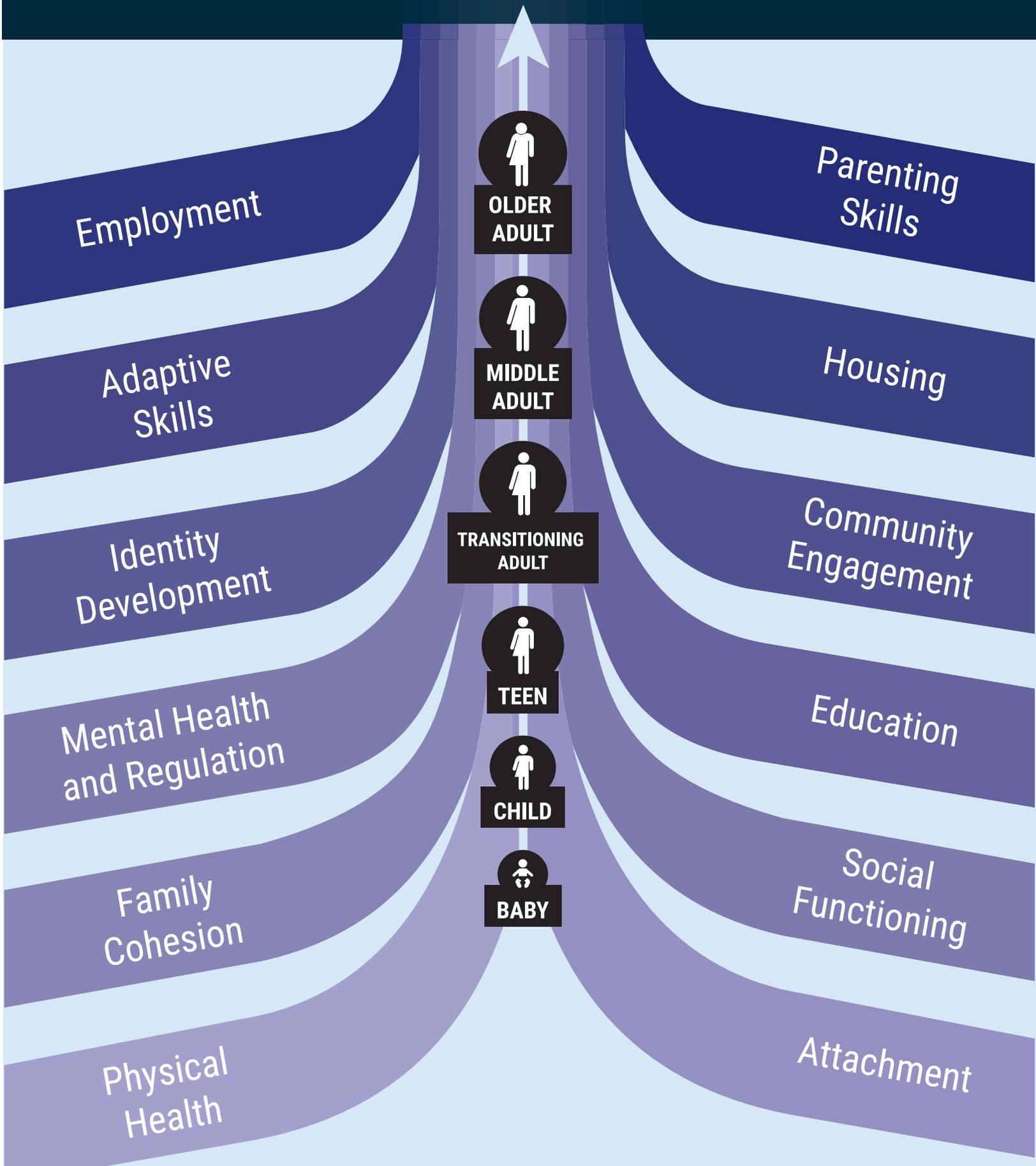


FIGURE 1. Philosophical Model

TOWARDS HEALTHY OUTCOMES FOR INDIVIDUALS WITH FASD



DOMAINS

We have identified twelve domains of intervention approaches that are common for individuals with FASD, and important for promoting well-being in all individuals.

PHYSICAL HEALTH

Physical health is fundamental to daily functioning and encompasses all the medical and physical components of health. Regular check-ups with a family physician have been identified as a component of healthy outcomes. For individuals with FASD, supporting physical health needs from early ages and through the lifespan is critical. Individuals with FASD may present with higher rates of health issues compared to the general population, and health issues may emerge at younger ages than typically expected. Some common health issues associated with FASD include impaired growth, vision, hearing, heart defects, seizures, weakened immune system, sleep, nutrition, elimination concerns, and dental health (Hanlon-Dearman et al., 2015). With interventions including medications, surgeries, nutritional supplements, health education, and exercise, individuals with FASD can manage and mitigate these health concerns (Hanlon-Dearman et al., 2015; Murawski, Moore, Thomas, & Riley, 2015).

ANTICIPATORY GUIDANCE FOR SUPPORTING AND MANAGING PHYSICAL HEALTH NEEDS IN FASD

To ensure optimal physical health, primary health care providers (PHCP) are required to monitor ongoing health support for their patients. PHCP often act as an advocate for their patients by consulting with other professionals and providing referrals for both medical and community support services. PHCP are particularly crucial in optimizing FASD patients' health given that individuals with FASD may present with numerous physical health concerns requiring medical intervention or need assistance in accessing community resources. To support individuals with FASD in their daily functioning, a multidisciplinary team has been recommended as the gold standard to help support patient's needs. Team members may include a psychologist, speech, occupational and physical therapists, a family advocate, and a coordinator for case management (Chudley et al., 2005).

Hanlon-Dearman and colleagues (2015) created a template to guide PHCP in properly managing the associated health concerns present within the FASD population entitled Anticipatory Guidance for Children and Adolescents with FASD. A thorough evaluation provides PHCP with the information needed to ensure that the individual's physical health requirements are properly met to promote improved daily functioning throughout the individuals' lifespan. The template is a great resource to facilitate this process.

HEALTH INTERVENTION APPROACHES

Medications. As it stands, there is not one medication used for treatment of FASD. Because of this, PHCP are required to consider all presenting physical health conditions and comorbid disorders on an individual basis. Researchers have yet to determine an algorithm for medication selection. Common symptom clusters that are considered when prescribing medication based on each individual's physical and mental health include: hyperarousal, hyperactive/neurocognitive, cognitive inflexibility, and affect/mood regulation (Mela et al., 2018). As with any individual, PHCP should closely monitor symptoms following the prescription being made to ensure the medication is optimizing daily function.

Nutritional Supplements. Maternal choline supplementation during or following pregnancy has been identified as a potential intervention and researchers using animal models have shown improvements in cognitive and motor functioning (Ryan et al., 2008; Thomas et al., 2009). However, only one clinical study has shown significant improvements in information processing in six-month old infants from mothers treated with choline during pregnancy. Researchers recommended that additional clinical trials be conducted to determine the effectiveness of choline in a wider range of cognitive domains in children (Akison et al., 2018).

Health Education. Any individual referred for concerns relating to their physical health requires education from PHCP in managing and mitigating their presenting concerns. For individuals with FASD, PHCP have their opportunity to educate and empower these patients and their caregivers to navigate through the medical challenges they may experience to ultimately improve their daily functioning. Through medication education and referrals to health promotion community resources, individuals with FASD and their caregivers can develop their skillset necessary to optimize physical health outcomes.

Physical Activity. Physical activity promotes physical health for all individuals. Participation in positive recreational activities is not only crucial to an individual's health but it also provides opportunities for "teachable moments" and experiencing success (Jones, 2004; Wirzba, 2013). Individuals with FASD should also engage in regular physical activity. It is recommended that this activity be extracurricular in nature and allow for opportunities to engage socially with their peers to also promote their social functioning (Jirikowic, Gelo & Astley, 2010).



ATTACHMENT

Attachment refers to the emotional bonds between caregivers and children that provide a sense of stability and security. These early relationships are foundational for future relationship development and attachment is recognized as a fundamental biological regulatory system that shapes an individual's behaviour. For example, children who undergo impaired attachment experiences, adverse early life experiences, and multiple caregivers in their early years are at risk for greater difficulties with interpersonal, psychosocial, and relational functioning later in life. This is a significant risk for children with FASD (Jacobson & Jacobson, 2003). Conversely, it is also an area where researchers have begun to demonstrate the positive impacts that are possible for children and families through trauma informed, attachment-based support and education for caregivers in addition to stable home placements.

INTERVENTION APPROACHES

Early Parent-Child Relationship.

Intervention in which the parent-child relationship is supported in infancy and early childhood have been effective at preventing adverse outcomes in high risk children and improving family functioning (Cicchetti et al., 2006; Bernard et al., 2012). Interventions developed under the dual attachment and trauma informed lens have the potential to have positive impacts for children and families. For example, Child-Parent Psychotherapy (CPP), is a relationship-focused, reflective, and developmentally attuned model of psychotherapy for young children with

histories of trauma, maltreatment, and associated problems with behaviour, self-regulation and posttraumatic stress (Lieberman, Silverman, & Pawl, 2000). The principle goals of CPP include: 1) creating safety in parent-child relationships and surrounding environments, 2) expanding parental responsiveness/attunement, 3) promoting parental capacity to balance parent and child needs, and 4) modifying maladaptive perceptions of parent and child for both members of dyad (Toth et al., 2018). The program allows for flexibility in administration based on the child's age, trauma history, and caregivers' functioning. When implemented in a sample of young children with FASD there was improvement in child developmental functioning and parents' caregiving skills (Zarnegar et al., 2016).

Caregiver Education in Adolescence.

Attachment informed treatments are also important beyond infancy and early childhood. Researchers have begun to identify the importance of attachment security in adolescence in predicting adaptive functioning and attachment in early adulthood and later in life (Collins, Cooper, Albino, & Allard, 2002; Pascuzzo, Cyr, & Moss, 2013). Because of this, researchers have developed interventions to promote security between teens and their caregivers. The Connect Program has been developed for caregivers of adolescents with complex mental health and behavioural problems (Moretti, Braber & Obsuth, 2009). The program is intended

to increase caregivers understanding of the behaviours they are seeing and make connections to the underlying attachment circumstances that may be 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 safe haven and secure base (Moretti, Pasalich, & O'Donnell, 2017). Preliminary evaluation of the Connect Program has produced promising results, including reductions in caregiver reports of adolescents' oppositional, aggressive, and antisocial behaviour, as well as decreases in anxiety and depression. Parents also reported increases in their sense of caregiving efficacy and satisfaction (Moretti & Obsuth, 2009).

Treatment gains were maintained a year later, and caregivers reported additional decreases in adolescents' externalizing and internalizing symptoms over time (Moretti & Obsuth, 2009). One of the hallmark features of Connect is the emphasis on attachment theory driven principles. For example, the program acknowledges that attachment is a basic human need that shapes behaviour and that the need for attachment continues throughout the lifespan, but how it is expressed changes across the lifespan (Moretti et al., 2018). These principles guide and inform intervention implementation. Although the program has not been tested with an FASD population specifically, caregivers may benefit from an attachment informed education to reduce their adolescents' problem behaviours stemming from disrupted attachment experiences.



STABLE HOME PLACEMENTS

All children and adolescents who are removed from their home not only face disruption in their previous attachment relationships, but also face the task of forming attachments to their new caregivers. It is possible for these infants and children to organize their attachment behaviour and form secure attachments to new caregivers, yet children with FASD may be exposed to multiple caregivers which in turn can have a negative impact on development across the lifespan (O'Connor et al., 2002). One way to reduce the number of caregivers a child is exposed to is to increase home stability. Home stability is associated with numerous positive outcomes for individuals with FASD including a reduction in the severity of behaviour and social problems and the frequency to which secondary disabilities occur (Streissguth, 1997; Streissguth et al., 2004).

Researchers have begun to examine what factors promote home stability for children in care. A factor identified by researchers to decrease the number of home placement changes is regular caseworker contact and support in addition to specialized training for FASD workers and foster caregivers (Pelech, Badry, & Doust, 2013). One intervention, Promising Practices, for children and adolescence suspected or diagnosed with FASD in out-of-home care, includes the core components of collaborative support plans developed with caseworkers, foster care support workers and foster parents, caseworker and foster parent training, and respite care. (Pelech et al., 2013). Home stability is a protective factor for all children who have been removed from their home. Given that individuals with FASD may experience multiple caregivers, assembling a dedicated, educated team to promote home stability has the potential to allow the child to form attachments to their new caregiver.





FAMILY COHESION

Family cohesion is an expression of belonging and acceptance within the family (McKeown et al., 1997). It encapsulates the emotional bonds that family members have with each other (Olson, Russell, & Sprenkle 1979). High family cohesion can act as a protective factor against adverse outcomes (Cumsille & Epstein, 1994; Marsiglia, Parsai, & Kulis, 2009). Specifically, it is understood that alterations in the caregiving environment can help to ameliorate difficulties experienced by children with FASD (Olson, Oti, Gelo, & Beck, 2009). In all families, how a family deals with typical and atypical stress plays a role in children's adjustment and adaptation (Mash & Wolfe, 2017). Heightened caregiver stress is related to negative family factors, including coercive interactions, increased risk of maladjustment, and parental depression (Plant & Sanders, 2007). Family cohesion includes safety, stability, education, and resources that families need to be strong together. Family cohesion involves the unity of caregivers, siblings, and extended family of an individual with FASD. In order to best support a child with FASD, families should try to provide a nurturing and secure home environment, structure and routine, and act as an advocate for the individual with FASD (Streissguth, 1997).

POSITIVE PARENTING

Parenting a child with FASD is different than parenting a typically developing child; needs in this domain include interventions to target parental stress, parenting skills, increase caregiver FASD education, and increase family resources. There are some promising interventions that target family cohesion including the Coaching Families program (Leenaars, Denys, Henneveld, & Rasmussen, 2012), Mindful Parenting Education (Bogels, Lehtonen, & Restifo, 2010), Parents Under Pressure (Chamberlain, Reid, Warner, Shelton, & Dawe, 2017), and Families on Track (Petrenko, Pandolfino, & Robinson, 2017).

MENTORSHIP

Some programs that have helped families raising a child with FASD use mentorships models that allow for a positive and trusting working relationship between caregivers and mentors. For example, the Coaching Families program uses mentors to provide caregivers with education about FASD, access to resources, and advocacy support (Leenaars et al., 2012). The Families on Track program (Petrenko et al., 2017) integrates in-home parent behavioural consultation based on the Families Moving Forward program (Bertrand, 2009) where key risk and protective factors such as family interaction patterns, child behaviour problems, and parenting attitudes are targeted.



MINDFULNESS

Other programs that have demonstrated success include emphasis on mindfulness of the caregiver and child's experience. Mindfulness is a psychological process of bringing attention to the present moment and adopting a non-judgemental and accepting attitude. Mindful Parenting Education (Bogels et al., 2010; Duncan & Bardacke, 2010) is a program that emphasizes reflection, empathy, compassion, and regulation. Programs also use mindfulness strategies to promote positive self-regulation strategies

in caregivers and their children, as seen in the Parents Under Pressure program (Chamberlain et al., 2017). Self-regulation is the ability to manage thoughts, impulses, and emotions and is a noted challenge in children with FASD. Consistent and predictable parenting is associated with improved regulatory skills in young children (Pears et al., 2015), and the capacity to manage emotions when children have self-regulatory difficulties can be a challenge for parents of children with FASD.



These programs target regulation using mindfulness strategies and use modeling of parent regulation to improve child regulation.

ONLINE RESOURCES

In addition, CanFASD has developed a caregiver resource guide *I Am A Caregiver!* (Badry & Hickey, 2018) that provides information for caregivers about raising a child with FASD. There are also other resources that can be found online to educate caregivers and families about FASD, offer tips and strategies, and direct them to avenues of support.

These online resources create accessible information for caregivers raising children with FASD to increase their education about FASD, information about services and resources, and ultimately increase family cohesion.

[Click Here!](#)

SOCIAL FUNCTIONING

Social functioning involves applying interpersonal skills to social interactions in order to initiate and maintain relationships. Social functioning can be challenging for some individuals because it requires them to draw on cognitive, behaviour, and emotion related information. This information is likely to interact with environmental factors which could produce a broad spectrum of deficits in social skills necessary in the context of a social interaction. Problem behaviours may occur when an individual has not acquired the social skills necessary for an interaction or has difficulty in performing a social skill (Gresham, 1981). Social skills are an adaptive behaviour and addressing problem behaviours typically involves teaching an alternate response related to a specific social skill to improve one's social functioning (Matson, 2017). Often, individuals with FASD have difficulty with social interactions and these difficulties have been found to increase with age. However, with intervention approaches individuals with FASD can improve their social skills.

SOCIAL SKILLS TRAINING

Social skills training (SST) programs designed to establish new skills or improve previously learned skills focus on increasing the frequency of specific responses in order to have these responses translate to the appropriate context on a consistent basis (Matson, 2017). Generally, it is understood that SST programs have not accounted for the unique learning, cognitive and behavioural characteristics of differing patient

populations. When developing targeted interventions to improve upon social skills and promote social functioning, it is necessary to be considerate of both strengths and weaknesses unique to the individual with whom you are working with. To date, targeted, evidence-based interventions such as the Children's Friendship Training program (CFT; Frankel & Myatt, 2003) have been adapted and has shown to be effective for children from various clinical populations including Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD; Frankel, 2005; Frankel, Myatt, & Cantwell, 1995; Frankel et al., 1997) and FASD (O'Connor et al., 2007). Specific to FASD, adaptations made to the intervention program have demonstrated efficacy in improving social performance and decreasing problem behaviours in children (O'Connor et al., 2006). Additionally, an intervention that taught social cognitive skills has also been conducted as a case study and demonstrated promising results (Timler et al., 2005). Although manualized programs, such as CFT, are not readily available to each and every individual with FASD, it is important to consider what adaptations were made and what techniques were used to make it a successful program for the individuals it was delivered to. This information can aid educators and caregivers in developing their own interventions to optimize an individual's success in their social interactions and promote social functioning while engaging the individual.

Laugeson et al., (2007) outlined several recommendations and considerations for adapting CFT for individuals with FASD. Similarly, strategies were used in Timler and colleagues (2005) case study that are also important for consideration in intervention development. Adaptations and strategies outlined in both intervention studies include considerations of learning and language, memory and executive functioning, and social cognitive challenges that may be present in an individual with FASD.

LEARNING AND LANGUAGE

Laugeson and her colleagues (2007) recommended several strategies to ensure comprehension of material. For example, it was recommended to break down material into simple components. One of the hallmarks of CFT is parental involvement to increase a child's social networks. For a

child to develop a social relationship, the child must use an appropriate entry technique in order to have a positive interaction with a peer. By breaking down peer entry into a simple, three-step process of watching, waiting and asking, children can appropriately approach their peers. The simplicity of this three-step process may allow for generalization outside of practice with their parents. Other learning and language recommendations in developing targeted interventions were created to ensure comprehension of material and translation of the skills to real life social situations. The authors recommended presenting information in multiple formats (i.e., verbal and nonverbal), the use of buzz words (i.e., simpler terms for more complex social skill topics), summarization of children's responses and considering the child's developmental level when using language.



MEMORY AND EXECUTIVE FUNCTIONING

Many children, including those with FASD, have difficulties with memory and executive functioning. Executive functions are a system of higher order cognitive processes that support goal-directed behaviours (Khoury, Milligan, & Girardi, 2015). These executive functioning difficulties may make retaining and using information learned in an intervention setting difficult. Two recommendations made by Laugeson et al, (2007) included increasing the use of verbal prompts and role playing. Role playing is of particular importance to facilitate the learning process and to allow for practice in a number of social scenarios. Role playing was a component of the social communication intervention developed in Timler and colleagues' (2005) case study and was shown to be beneficial. The intervention included role playing of social scripts in which the client and her peers assumed both adult and child roles. A checklist was developed to guide the children through a routine for resolving social situations encountered. The clinician facilitating the intervention was responsible for modeling socially appropriate responses for the children prior to role play and use of the checklist. Laugeson and colleagues also recommended the inclusion of homework rehearsal and the regular review of intervention tactics and components when adapting or developing social skills interventions (Laugeson et al., 2007). This is crucial for consideration because it provides children with the opportunity to

remember and practice steps to use when entering into or maintaining a peer interaction.

BEHAVIOUR

Many children in social skills interventions present with specific behavioural challenges. Therefore, it is recommended that along with the social skills training children be provided with additional behavioural interventions (e.g., token system) to increase the likelihood that the child is able to complete the intervention (Laugeson et al. 2007). Additional recommendations included regularly reviewing clear and explicit rules, and positive reinforcement techniques to increase the occurrence of positive targeted behaviours.

SOCIAL COGNITIVE SKILLS

Children with FASD may make inappropriate statements and poor-quality social overtures and their responses in social contexts may be overly friendly or uninhibited (Bishop et al., 2007). An important targeted area for intervention to improve one's social communication skills is to target perspective taking (i.e., theory of mind) and thought processes involved in social interactions. Timler et al., (2005) used role play of social scripts where the child and her peers assumed both adults and child roles, a checklist for resolving social situations and clinician modeling of socially appropriate responses.

You can find some resources for teaching social skills to children with FASD here:

[**Click Here!**](#)

MENTAL HEALTH AND REGULATION

Mental health refers to emotional and psychological health and disorders. Mental health disorders affect many people, but in particular, those with FASD are more likely to have mental health concerns than typically developing children (Pei, Denys, Hughes, Rasmussen, 2011). One factor that impacts mental health is the ability to regulate cognitions, emotions, and behaviours (Kriston & Piko, 2017; Woodward, Lu, Morris, & Healey, 2017).

Gill and Thompson-Hodgetts (2018) found a definition of self-regulation specifically for individuals with FASD. They state that “in relation to the FASD population, self-regulation is defined as an individual’s ability to recognize and adapt his/her response in order to engage in deliberate and thoughtful actions while reminding attentive, inhibited, and emotionally appropriate for the situation or context” (Gill & Thompson-Hodgetts, 2018, p. 15). Due to underlying executive functioning difficulties, self-regulation can be challenging for individuals with FASD. When executive functions such as inhibition (the ability to stop an automatic response) are compromised, it is difficult for an individual to regulate, which can lead to behavioural problems and increased mental health concerns (Barkley, 2001; Woodward et al., 2017). Mental health concerns including addictions, depression, anxiety, ADHD, conduct disorder, and suicidal ideation are important to address to promote healthy functioning in individuals with FASD (Pei et al., 2011).

INTERVENTION APPROACHES

Researchers have shown that targeted interventions can improve self-regulation to ultimately help individuals stay calm and attentive and improve mental wellness (Coles, Kable, Taddeo, & Strickland, 2015; Nash et al., 2015). Interventions to improve self-regulation include increasing awareness of regulation states, teaching metacognitive strategies, and using sensory tools.

AWARENESS OF REGULATION STATES

Increasing awareness of regulation states refers to coaching individuals to tune into their current physical and emotional state and identify how they are feeling in the moment. By purposefully paying attention to your current regulation state, individuals will increase their self-awareness, and be able to change or monitor their regulation more effectively. Additionally, increasing awareness of regulation states offers a chance for individuals to communicate how they are feeling, and access supports if needed. An example of how to do this is using the analogy of engine speeds from the Alert® program (Williams & Shellenberger, 1996). Children use a visual tool to help them identify if they are feeling “high”, which would include hyper or energetic, “low”, which would include tired or bored, or “just right” which includes feeling calm and focused.

Another example of identifying regulation states is the Zones of Regulation® (Kuypers, 2011). In this program, colours are used to identify if you are feeling “blue”, which may be sad or tired, “green” which may be happy or calm, “yellow” which might be frustrated or worried, or “red” which would include feeling angry or scared. Once children are taught to check in with themselves and identify how they are feeling, they can then use strategies that may help them to reach their optimal regulation state as alternatives to acting out with negative behaviours.

METACOGNITIVE STRATEGIES

Another approach to improve regulation and mental health includes teaching metacognitive strategies. Metacognition is the process of thinking about thinking and using various strategies to meet one’s goals. Metacognition is one’s inner dialogue and includes self-knowledge about a person’s own cognition and the ability to influence your own cognition (Flavell, 1949). Using this approach, children are coached to think about and monitor their learning with active strategies (Thompson & Thompson, 1998). Metacognition promotes the development of learning strategies, generalization of skills, and generates positive functional outcomes (Cicerone et al., 2011). A few examples of metacognitive strategies include rehearsal, chunking, positive self-talk, and deep breathing. In a study examining metacognitive strategy use during a computer-based intervention, children with FASD were found to use 26 different metacognitive strategies, and

eight of those were used spontaneously by all participants. This study shows that with coaching, children with FASD can increase their autonomy in using a variety of strategies (Makela, Pei, Kerns, MacSween, Kapasi, & Rasmussen, In Press). One example of a metacognitive approach that has been used with children with FASD is the FAR intervention, which stands for Focus and plan, Act, Reflect (Coles et al., 2015). By explicitly teaching children to use these metacognitive steps when approaching a task, children can learn to approach problems thoughtfully rather than responding in an impulsive manner. Children then perform the plan and reflect back on what worked or did not work (Coles et al., 2015).

SENSORY STRATEGIES

Sensory strategies can be beneficial for children with FASD to help them self-regulate. The Alert® program discusses five ways to regulate, which are mouth, move, touch, look, and listen. By exploring different strategies in these sensory categories, children with FASD can create a toolbox of personalized strategies that help them self-regulate. For example, in the mouth strategy, an individual may select crunchy snacks, or blowing bubbles as ways to regulate. In the touch category, they may enjoy petting an animal, or have a favourite blanket that helps them feel “just right” (Williams & Shellenberger, 1996).

IMPROVING MENTAL HEALTH

Mental health can be supported through counselling and psychotherapy that is tailored towards the client and considers their FASD diagnosis in treatment (Tremblay, Pei, Plesuk, Muchortow, Mihai, Jordao, 2017). A model of FASD-informed clinical practice describes three components to counselling with individuals with FASD: reflection, communication, and action. Counsellors working with children with FASD are encouraged to participate in reflective practice regarding the clinical process. Multiple levels of communication are also key when counselling individuals with FASD, including between counsellors and other service providers, supervisory staff, and FASD consultants. Thirdly, counsellors must be active in their approach, and use practical and pragmatic strategies when working with this population. When working with adolescents with FASD, program staff describe success when they work with both parents and adolescents to teach them important psychoeducation and stress coping skills. One program that has found some success using this approach is Project Step-Up, which targets addictions (O'Connor, Quattlebaum, Castaneda, & Dipple, 2016). Project Step-Up provided weekly groups for parents and adolescents to prevent and reduce alcohol use by focusing on providing alcohol education, fostering coping skills, and teaching adaptive responses to substance-related social pressure (O'Connor et al., 2016).

You can find more information about mental health and FASD on the CanFASD website:

[Click Here!](#)





EDUCATION

The education system in Canada aims to provide the academic and functional supports necessary for students to complete their school years and transition into independent adults who are able to successfully navigate through their occupational and social worlds. Upon school entry, academic and educational demands are placed upon all children, and difficulties may emerge for students in variety of core curricular areas such as reading, writing, or mathematics (Millar et al., 2017). Similarly, children may present with behavioural challenges associated with transitioning to an increase in structure and unfamiliar routines. Like others their age, children and adolescents with FASD may also present with learning difficulties in core curricular areas and/or behavioural difficulties as a result of their unique and complex pattern of neurocognitive and behavioural characteristics. How do we go about thinking to provide individualized support and engage these children throughout their school years? Through functional assessments, individualized adapted learning plans, extra assistance and targeted interventions, children and adolescents with FASD can improve their academic skills and succeed in school.

FUNCTIONAL ASSESSMENTS

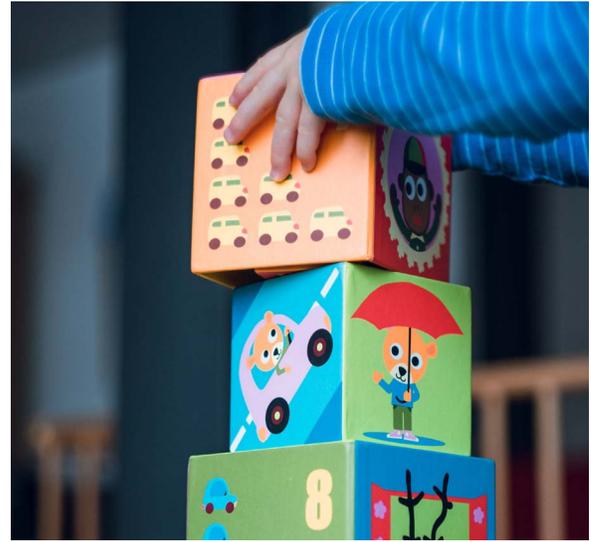
Following a diagnosis of FASD, experts recommend conducting a functional assessment (Kalberg & Buckley, 2006; Maag & Larson, 2004). This is to proceed the development of an

individualized education plan (IEP) to assess the student's current skill levels and unique needs they have in the school setting (Kalberg & Buckley, 2006). Often classroom expectations regarding academics and behaviour are communally defined. A functional assessment allows educators to determine what is functional for the classroom and what is functional for the individual student. The information gathered during this process allows goals to be developed based on a student's unique pattern of strengths and challenges. These goals should not only engage the student but promote their academic and behavioural functioning in the classroom setting. The functional assessment should begin with comprehensive observations in a variety of classroom situations to determine the child's functional capacity, from a behavioural and academic standpoint. This will yield information regarding situations or circumstances that optimizes the child's success. Kalberg & Buckley (2006) outlined the following key factors to be evaluated during the observation periods: 1) skills; 2) attention; 3) independence; 4) social interactions; 5) functional language; 6) strengths and interests; and 7) behaviour. This information can be used to supplement diagnostic testing results, and background information in the development of an IEP to support each student's unique pattern of learning and behavioural strengths, interests and needs.



DIAGNOSTIC TESTING RESULTS

For many students, school may be the first environment in which complex learning difficulties and behavioural challenges are brought to caregivers' attention. Educator identification of each student's unique learning and behavioural needs could prompt a referral, with caregiver consent, for further testing to aid in the development of individualized supports. For students with FASD, in order to receive a formal diagnosis, they take part in a multidisciplinary assessment. This assessment highlights each child's unique and complex set of neurocognitive and behavioural characteristics. One important component of the assessment is the information provided on memory, problem-solving, and inhibitory control (Millar et al., 2017). This assessment information is valuable to educators. Researchers have begun to document the importance of moving towards an assessment *for* intervention approach where assessment results are used



to inform intervention decisions (Pei et al., 2013). Assessment for intervention is crucial to supporting the academic success of students with FASD, among others, for three reasons. First, assessment and diagnosis are only as useful as the recommendations and supports provided. Second, students with FASD present with varied learning and behavioral needs which require assessments that are designed to inform intervention practices to achieve the best possible outcomes for these students. Finally, it is crucial to provide support to educators and to include them in the assessment process because their expertise is highly valued in the decision-making for educational programming and intervention. All assessment results can be used to inform the development of the student's IEP and educational decisions and intervention planning can be made in a collaborative manner with educators, caregivers, and allied professionals alike to support individuals with FASD in achieving positive academic outcomes.



ACADEMIC INTERVENTION APPROACHES

Targeted interventions in language and literacy, as well as math have demonstrated positive academic and behaviour outcomes for children with FASD (Adnams et al., 2007; Coles et al., 2009; Kable et al., 2007). Targeted interventions have components that work well in supporting students with FASD complete academic work tasks. These interventions employ metacognitive strategies, involve multisensory stimulation exercises, and are individualized and tailored to meet students' needs to foster the development of specific academic skills (Adnams et al., 2007; Kable et al., 2007).

A resource for educators of individuals with FASD:

[Click Here!](#)

You can learn more about education and FASD here:

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IDENTITY

Adolescence is a period of notable identity development, where individuals are looking to distinguish their qualities, values, and self-perception. According to Erikson's theory of development, adolescence is the time during which earlier identifications from childhood are evaluated and ultimately defined by assimilating childhood and adolescence experiences. The adolescence's perception of how society views them also impacts these identifications (Kroger, Martinussen, & Marcia, 2010). As of yet, there is no determined course of the lifelong process in which identity development occurs, and there is still uncertainty regarding the timing and general order by which individuals develop self-identity (Kroger et al., 2010).

IDENTITY DEVELOPMENT IN ADOLESCENCE

Late adolescence and early adulthood are also times of important life changes, including transitions in living situations, education, and employment status. Important choices are made during this time that can impact an individual's identity and may include career and education goals; philosophical, moral, and spiritual/religious choices; self-expression across various domains including gender and sexual identities (Kroger et al., 2010). Four levels have been outlined as commitment to, and engagement with, identities across these areas during the process of identity development. The final stage, identity achievement involves commitment to an identity following exploration, and is

generally believed to be attained by adulthood (Kroger et al., 2010).

As individuals progress through adolescence, they undertake new roles and responsibilities. All of these factors combine to add to any challenges an individual may already be facing. Just as everyone requires unique support and guidance as their independent identity forms, so too do those with FASD and therefore supports and accommodations may be necessary to help navigate the transitions period of adolescence (Burnside & Fuchs, 2013).

There is limited understanding regarding the identity development differences that may be specific to adolescents with FASD. Although all adolescents likely undergo a similar process of identity formation, it may be altered for those with FASD due to differences in cognitive abilities. Although the research for the identity development of this population is limited, there are researchers who are investigating the self-perceived identity development in adolescents and adults with FASD, primarily via qualitative interviews.

Adolescents with FASD in Manitoba who were transitioning to independence from government care shared their lived experiences during this time. While many of the adolescents with FASD looked forward to emancipation upon reaching the age of majority, many also conceded

there were skills they needed to learn. The adolescents shared the challenges and opportunities they had faced in trying to exert greater independence throughout adolescence (Burnside & Fuchs, 2013). The primary challenges shared by adolescents with FASD were the limitations placed on them because of their diagnosis along with their involvement in the child welfare system. Many of the adolescents viewed that the liberties afforded to their peers, such as being able to visit friends or family as they wished, were not afforded to them. Additional challenges included being active parents at the time of the study, completing their high school education, and experimentation with drugs and alcohol. Adolescents with FASD also shared feeling isolated in their long-term planning despite requesting support from their workers during this process. The authors speculated that these adolescents may have benefited from more in-depth planning for their emancipation with their workers and opportunities for the development of skills related to independent living (Burnside & Fuchs, 2013).



IDENTITY DEVELOPMENT IN LATER LIFE

Identity development does not end with adolescence, but rather continues to evolve as individuals age. Through the actions and words of others, the identity of an individual with FASD is often reflected back to them. Four adults who had been diagnosed with FASD later in adulthood were interviewed to determine its impacts on their self-concept (Erb, 2015). Many adults with FASD explained that the diagnosis marked a turning point in their lives. Prior to receiving their diagnosis, the adults had sensed they were different and by becoming aware of their FASD, they were able to begin to make sense of their experiences (Erb, 2015). This newfound knowledge helped them to create a greater self-understanding and life purpose. The author reinforced the importance of continued identity evaluation through adulthood through ongoing assimilation of information from ourselves and our environment (Erb, 2015).

Adolescence and young adulthood are key in the formation and development of identity, though it does continue throughout adulthood. Identity formation is based on exploration of past experiences, current social environment, and knowledge base (Kroger et al., 2010). This period is often marked by increased responsibilities and independence for adolescence, including those affected by FASD. Ongoing evaluation, support, and accommodation is necessary to help individuals with FASD develop and maintain a positive identity.



COMMUNITY ENGAGEMENT

Community engagement refers to a sense of belonging to a community and involves having things to do, having a social network, access to medical and social services, and independence (Clark, Minnes, Lutke, Ouellette-Kuntz, 2008). The desire to belong to a community is an important and natural part of our lives and having a sense of belonging to a community is a positive influence on well-being (Cummins & Lau, 2003). The joy of community integration is not only based on physical involvement, but also based on a psychological sense of community (Cummins & Lau, 2003). This psychological sense of community can be explained as the feeling of being part of a readily available, supportive, and dependable structure (Sarason, 1977). When individuals experience connectedness, interdependency, and belonging, they experience a sense of community. Active engagement in community initiatives can have valuable psychological consequences, including boosting self-esteem and confidence. In addition, community engagement may have an impact on an individual's sense of empowerment. People who are actively involved in a range of community activities have reported physical and emotional health benefits, such as improved fitness and nutrition, and more feelings of happiness and less feelings of loneliness, depression, or anxiety (Attree et al., 2011). In disability populations, it is important to promote integration into the community, where disability related needs are identified and supported by the community. Community Living BC has put out a guide that provides more information about community engagement.

For those with disabilities, physical exposure is necessary, but not sufficient, to foster community engagement. Especially in individuals with limited social skills, simply going out into the community or bringing people together for a recreational purpose is not necessarily going to contribute to a sense of community engagement. It is social engagement that is linked to subjective well-being (Cummins & Lau, 2003). Creating opportunities for individuals with FASD to socially integrate into the general community, and also to develop communities of their own with other individuals with FASD may contribute to a greater sense of well-being (Cummins & Lau, 2003). Cummins and Lau (2003) argue that one's sense of community is enhanced by active association with selective members of one's family and friends with whom a common interest is shared. Often caregivers are integral in helping individuals with FASD integrate into communities (Clark et al., 2008). Greater family involvement and social support have been found to be related to increase community participation and independence (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009a). Verdonschot et al. (2009a) reported that opportunities to make choices, variety and stimulation of the environment, opportunities of involvement in policy, small residential facilities, opportunities for autonomy, and vocational services were environmental factors that all contributed to positive impact

You can find it here:

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on community participation for individuals with a disability. Assistive technology was also identified as a factor of influence to enhance interdependence and social engagement. As disability policies have shifted focus from an intrapersonal approach to a social ecological approach, community participation has been included as an essential dimension to human functioning (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009b). Milner & Kelly (2009) reported five attributes that emerged from their research on participatory membership and belonging with individuals with disabilities. They found that a sense of self-determination, social identity, reciprocity and valued contribution, participatory expectations,

and psychological safety all contributed to a sense of community belonging. Some ways in which to facilitate community engagement with individuals with FASD are promoting self-chosen activities that allowed a degree of autonomy, identifying and focusing on places where individuals feel known and can establish positive self-identities, emphasizing opportunities for reciprocity and contribution as a way to challenge implied dependence, and finding opportunities to allow individuals with FASD to be challenged and have expectations. Lastly, ensuring psychological safety through a trusting and accepting community is important to encourage community engagement.



ADAPTIVE SKILLS

Adaptive skills describe daily living skills, which gradually allow individuals to become independent and integrate into society. Adaptive skills are based on developmental and sociocultural standards for personal independence and social responsibility (Mash & Wolfe, 2018). Adaptive functioning is age dependent and characterized by performance. Importantly, adaptive skills are not solely related to ability, but also opportunity and experience. Adaptive skills are comprised of three domains: conceptual, social, and practical. Conceptual adaptive skills include functional use of reading, writing, and math. Social adaptive skills include communicative behaviours, capacity for relationship development, and understanding social cues. Practical adaptive skills involve grooming, dressing, hygiene, and eating. All children show a considerable range of abilities and interpersonal qualities, and so their adaptive skills vary, and may be stronger in some areas than others (Mash & Wolfe, 2018).

INTERVENTION APPROACHES

Often, individuals with FASD have difficulties with various daily living skills, functional communication, and community living skills, however with appropriate strategies, adaptive skills can be improved (Ase et al., 2012). For example, one intervention that has demonstrated some success to increase adaptive skills is a computer program to teach children with FASD fire and street safety. While executive functioning skills are developing, a lack of planning or awareness of consequences may result in physical danger for children with FASD. Using a computer game that employed a virtual world stimulation, four concrete safety skills are taught in small steps, and dangerous or incorrect

movements are restricted (Coles, Strickland, Padgett, & Bellmoff, 2007). Experiential approaches to learning are beneficial for individuals with FASD to provide concrete and tangible information. Adaptive skills are also easily modeling, rehearsed, and reinforced. Children with FASD may require more explicit support and structure to learn adaptive skills, including repetition, redirection, and visual cues. Breaking down skills into small tasks allows children to more easily follow the steps to help them with daily activities. Mentorship programs such as the WRaP (Wellness, Resilience, and Partnership) program can also be influential to promote day-to-day success and wellbeing for individuals with FASD. The WRaP program is situated in Alberta schools, and provides strength-based supports to children and adolescents affected by FASD. WRaP mentors work one-on-one with individuals with FASD to guide and empower them in vocational, educational, and community supports, and be active members in society. The mentors also work with educators, community agencies, and other professionals to provide guidance and support in order to build the capacity of school personnel, develop community partnerships, and support student engagement, success, and social, emotional, and physical well-being. This program has found that genuine, safe, and compassionate relationships are key to facilitating growth and development of adaptive skills (WRaP, n.d.). There are some resources available online to assist with teaching adaptive skills.

For example, a resource that may be helpful for teaching about money is:

[Click Here!](#)



EMPLOYMENT

Anyone entering the workforce strives to find employment that suits their unique skills and interests while also providing a competitive wage, fair working hours, and opportunities for professional growth. Successful employment requires a balance between the employment environment and an individual's abilities, skills, and needs, which can be challenging in many circumstances. Integrated employment opportunities for individuals with cognitive or developmental delays, such as FASD, can be further limited due to a lack of information and understanding of this diagnosis and neurocognitive delays in general (Molls, Huff, & Detwiler, 2003; Green, 2016). Although a lifelong diagnosis, potential deficits associated with FASD are often circumvented with proper identification, education, and supports in place for the individual (Molls et al., 2013). Individuals with FASD often benefit from employment environments that are in line with the supported employment model. The supported employment model incorporates individualized guidance and a strength-based approach to find a good 'fit' between the individual and their employment environment, with the aim of maximizing their opportunities for successful employment (Green, 2016).

SUPPORTED EMPLOYMENT

The supported employment model calls for accommodations and built in supports for individuals with disabilities, with the aim of integrating clients with disabilities into the workplace setting. Meaningful employment

can be a benefit to the rehabilitative process of individuals experiencing prolonged mental illness and neurocognitive challenges, including those effected by FASD (Molls et al., 2003). With appropriate environment and individual balance, expectations on the part of employers, and supports and adaptations in place, individuals effected by FASD are capable of successful, long-term employment (Molls et al., 2003).

Individual differences exist among all people, and individuals with FASD are no exception. Although there are many examples of potential deficits associated with this diagnosis, securing employment requires a focus on the strengths and abilities of the individual. Strengths that are associated with FASD include a willingness to please others, persistence, non-judgmental attitudes, and being understanding of others (Community Living British Columbia, 2011).

One report, created by the Community Living Program in BC (2011), outlined areas of potential need and support options for individuals with FASD. For example, some individuals affected by FASD may struggle with keeping track of time, and this may be demonstrated by frequently arriving late for scheduled shifts or confusion around break times. By providing written reminders, programmed alarms in their personal phone or computer, and/or written instructions, these behaviours may decrease. In order to determine the potential underlying reasons

for an individual's behaviour, ongoing evaluation of the individual and their supports are required by those with FASD. By continuing to monitor each individual's needs and providing the necessary supports to improve an individual's skills, an individual with FASD's opportunities for employment success increases (Community Living British Columbia, 2011).

ACCOMODATIONS

Suggested accommodations for individuals with FASD included routine and consistency, clear and concise language, and/or multiple demonstrations of tasks. If possible, a job coach or support worker on-site or co-workers to provide supports, help, or advocacy. It is also important to encourage rest and recovery between shifts so as to prevent feelings of exhaustion or burn out in individuals with FASD (Community Living British Columbia, 2011).

A report was released by the Canada FASD Research Network (CanFASD) in which interviews were conducted with nine employment programs based in Alberta, British Columbia, Yukon, and Manitoba. Key findings included the critical need for relationship building between staff and clients, employer and organizations, and the role that education, awareness, and support play in the overall employment success of the individual (Green, 2016).

In response to this report, an employment tool Supporting Employment in Adults with Fetal Alcohol Spectrum Disorder was created by Makela and colleagues (2018) to provide specific information and support for employment programs working with individuals with FASD. By conducting surveys and interviews with individuals with FASD and their caretakers, the authors were able to create a guide that provides a standardized process to help adults with FASD obtain and maintain successful employment. The guide is organized by first acknowledging the importance of individual well-being in maintaining employment, followed by three categories of work factors: prepare, obtain, and maintain. This method of organization was meant to support the progression of clients through their employment experiences (Makela et al., 2018).



You can find the employment guide here:

[Click Here!](#)

HOUSING

Safe, affordable, and secure housing is a basic human right. Each person requires supports tailored to their unique needs, and individuals with FASD are no exception. Housing First was developed to better address the needs of individuals who were unable to participate in traditional continuum of care housing programs due to not meeting program sobriety or treatment requirements (Aubry et al., 2015).

HOUSING FIRST

Once enrolled in Housing First, clients are provided access to immediate, permanent housing in a private apartment unit of their choice based on market availability. Housing First programs help clients find the unit and secure rental subsidies. Throughout program delivery, Housing First emphasizes client choice, such as the unit location and type and participation in treatment or community programs (Aubry et al., 2015). Housing First programs have decreased homelessness for individuals with moderate to high needs, including those who are considered more difficult to house (Woodhall-Melnik & Dunn, 2016). Aside from the provision of immediate, permanent housing for individuals with moderate to high needs, there is no consensus in existing literature whether other factors, such as age or substance use, have any influence on the long-term maintenance of housing for any population, let alone for those with FASD (Woodhall-Melnik & Dunn, 2016; Benston, 2015). Although there are many studies examining the implementation of Housing First and its benefits compared to other programs, studies generally have only provided

information regarding psychiatric diagnoses and substance abuse disorders (Benston, 2015). There is very little research related to housing individuals with developmental disabilities, specifically individuals with FASD (Woodhall-Melnik & Dunn, 2016). Although individuals included in these studies often have moderate to high level needs, there is no established knowledge about the number of individuals with FASD who have been involved in housing programs.

A Canadian study of Housing First followed individuals for three years after program enrollment in either Housing First or community housing programs. After 12 months had passed, 73% of Housing First participants remained stably housed, compared to 31% of traditional program participants (Aubry et al., 2015).

LOCAL INITIATIVES

In Alberta, one of the first housing programs to provide housing specific to individuals with FASD is Hope Terrace. Hope Terrace provides housing in one building that offers one or two-bedroom suites to individuals with FASD who are also experiencing housing instability. Supports are provided by staff on-site 24/7 and include cultural, cooking, and life skill development opportunities. This program aims to create a sense of self-reliance within their clients, as opposed to independence, and provides long-term housing with no time limit. An evaluation was completed in 2017 and the results indicate an increase in

well-being and improvements in housing stability for most clients since entering the program (Bissell Centre & Werbia Consulting, 2017).

In November 2017 Canada FASD Research Network in partnership with the University of Alberta hosted a meeting with managers, care takers, and front-line service providers in the fields of housing and FASD from across Canada. The aim was to establish an understanding of housing and FASD services and any gaps that may exist when providing housing supports to individuals with FASD. Many attendees of the meeting noted that while programs may be based on Housing First principles, many service providers believe in and follow these principles to different extents. Attendees also indicated frustration with the ability of programs to respond to client needs as they change over time (Carlson, Mattson, Joly, Pei, & Poht, 2018). It was proposed by attendees that a spectrum of housing styles and program types should be made available to individuals with FASD based on their level of need.

Caretakers of individuals with FASD reported potential misunderstandings on the part of landlords, caretakers, or other service providers around the needs and behaviours of individuals with FASD that have occasionally resulted in evictions. These caretakers highlighted a need to improve relations between landlords, service providers, and tenants to allow for collaborative and proactive problem-solving in the face of challenges (Carlson et al., 2018).

You can find more information about CanFASD’s work in housing here:

[Click Here!](#)

There is little consensus around the housing needs and requirements of individuals with FASD. Based on several studies and conversations with frontline workers in the field, it can be concluded that many individuals with FASD can be successful to maintain long-term independent housing with ongoing, intensive supports.



PARENTING

The role of a parent is often demanding, as children require constant care, support, and nurturance into adolescence and adulthood. Many parents often require supports to foster their parenting skills as the needs of their children develop. The skills and abilities of each parent are heterogenous and constantly evolving, as are those of each parent with FASD. Adolescents and adults with FASD often aim to have a family (Burnside & Fuchs, 2013). Canadian estimates of the number of parents living with FASD are generally around 300,000 (Rutman & Van Bibber, 2011). In response, many community parenting programs have developed supports specific to parents with FASD. For more information regarding existing programs to support parents affected by FASD, please see the Asante Centre's website (www.asantecentre.org).

Parenting skills are often an area of concern not only to individuals with FASD, but to those who support them as well, and gaps may exist in the perception of parenting abilities between parents with FASD and their support workers (Abraham, 2005). When someone with FASD becomes a parent, some of the challenges that parents with FASD experience may be aggravated or made more complex than those who are not affected by FASD, however there is no link between cognitive capacity and parenting capacity (Abraham, 2005). Developing strong parenting skills in individuals with disabilities such as FASD presents a chance to create and develop existing coping skills in this population. With the proper supports and accommodations in place, individuals within this population are able to develop strong parenting skills (Rutman & Van Bibber, 2011).

BREAKING THE CYCLE

Parents who were diagnosed with FASD shared their insights into the goals, challenges, accomplishments, and strategies that they deployed. The primary goal reported by parents was “breaking the cycle”, the meaning of which varied by the parent. Some used this term to mean breaking the cycle of abuse in their families, while others used it to mean the pattern of substance abuse or addiction around their children. Regardless of the term's specific meaning, all parents reported wanting to create a better environment for their children than they had experienced as children (Rutman & Van Bibber, 2011). Parents attributed some stressors to FASD, including difficulties with memory, organization, and integrating sensory cues (Rutman & Van Bibber, 2010). They also described barriers in societal attitudes to their parental status due to their diagnosis, causing their parenting abilities to be scrutinized by all levels of society, and creating anxiety and feelings of inadequacy around their parenting abilities. Despite these barriers, parents were able to parent their children successfully (Rutman & Van Bibber, 2010).

STRATEGIES

Strategies that were used by parents to meet their parenting goals included frequent and regular use of calendars, highly detailed instructions and written schedules. Parents also reported using self-talk as they transitioned between activities, applying a consistent routine, and regular boundary setting. Parents identified focusing on the positive behaviours demonstrated by their children or taking a time-out for themselves to help remain calm when frustrated (Rutman & Van Bibber, 2010).

Individuals with FASD who had children, along with their caretakers and service providers indicated services or supports

that promote positive parenting and any gaps that existed for parents with FASD (Abraham, 2005). Parents articulated needing help with reminders around appointments, transportation, and support groups for FASD. They also stressed the need for parenting materials that are clear and understandable for those with FASD. Advocates indicated a lack of involvement of parents with FASD in decision-making processes, and that parents with FASD are not encouraged to express their opinions. Overall, the most common barrier reported by parents was a lack of FASD training of caseworkers and limited resources, time, and funding while enrolled in programs (Abraham, 2005).



ADAPTIVE PROGRAMS

Recently, there has been an increased effort by community programs to provide services specific to parents with FASD and their families. Presented below are two programs for parents with FASD that have been implemented and evaluated. Catholic Social Services in Edmonton AB, developed Step-by-Step, one of the first programs in Canada to provide specified supports for parents affected by FASD. This program offers mentors to parents affected by FASD for three years beginning in pregnancy. Mentors secure and strengthen community connections and supports, income and employment support, and stable housing as needed (Denys, Rasmussen, & Henneveld, 2011). Mentors also refer family members for neuropsychological assessments as required. Other supports offered by this program include addictions supports, crisis management, and recreation resources (Denys et al., 2011). The Step-by-Step program's effectiveness in helping parents with FASD achieve their parenting goals was evaluated. The three most common goals selected by clients were related to developing their community connections, parenting, and self-reliance abilities. The three most common needs clients reported were those related to family, parenting and peers, and behavioural problems (Denys et al., 2011). Overall, there was found to be improvements in client's goal attainment after completing the program, along with an improvement in their needs scores.

Mentors of this program shared that whereas advocacy and supports provision is important, much of a client's success is largely dependent on the stability in other domains of life, particularly by consistently having their basic needs met (Denys et al., 2011).

The Parent-Child Assistance Program (PCAP) was developed to target woman who are at risk of having a child with FASD (Grant et al., 2004). PCAP assigned case managers to 15 families for three years beginning during pregnancy. The primary goal of case managers is to provide positive and empathic relationships for clients. They assist clients with problem solving and referrals to community services (Grant et al., 2004). The FASD adaptation provided specific training for case managers and key community service providers, including FASD's potential symptoms, underlying causes of behaviour, and diagnostic process to improve the quality of services they offer. There was a decrease in the total number of clients using alcohol or drugs, and an increase in the number of clients who had secured stable housing (Grant et al., 2004). The program also emphasized the use of contraceptives, and most parents were engaged in family planning and contraceptive use by the end of the study. Overall, case managers helped parents with FASD increase their ability to access and the quality of services available to this population in the community. Like all parents, those affected by FASD ultimately wish to see create a better life than their own for their children (Grant et al., 2004)

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 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 creation of an intervention model for individuals with FASD is important 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 for Individuals with FASD is a model that will hopefully have widespread use for researchers, policy makers, professionals, family members, supporters, and individuals with FASD.



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