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Promising Interventions for Children with Suspected or Confirmed Fetal Alcohol Spectrum Disorder (FASD)

Abaya, A., DeJonge, B. & Rogachyova, N.

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability that affects the brain and body of people who were exposed to alcohol in the womb. FASD is prevalent in 4% of the population in Canada and makes up a disproportionate number of children in need of Ministry of Children and Family Development (MCFD) assistance in British Columbia (BC). People with FASD have unique strengths and challenges and require community and family support to maintain wellbeing. As such, MCFD anticipates expanding its services to reach more children and youth with FASD and requires information about best practices for supporting this population. The Ministry of Children & Family Development is looking to learn more about programs and practices for supporting children ages 3-12 with suspected or confirmed FASD to contribute to a collection of evidence-based interventions designed to support practitioners in delivering services to this population. This research aims to answer the question: What non-FASD-specific community-based programs and approaches have clinicians been finding promising for use with children with confirmed or suspected FASD? This exploratory study used online focus groups and interviews with professionals working with children and families with suspected and confirmed FASD to collate their thoughts on promising programs, approaches, and interventions. MCFD clinicians, community workers, and a researcher were recruited and asked semi-structured questions to better understand the practices and approaches they find promising for use with children with FASD. To this extent, 4 interviews and 1 focus group consisting of 3 participants were completed over Zoom. These interviews were transcribed, and a thematic analysis was completed. Three main themes were identified in the analysis.The first is understanding behaviours.Understanding behaviours entails increasing awareness, education, and training around the behavioural issues that arise for children with FASD. These include learning about developmentally appropriate interventions, acknowledging trauma, communication support, and consistent behavioural expectations. The second is creating spaces of inclusion. This means creating a physical, virtual, or metaphorical space where youth, parents, and service providers are able to connect with each other and people with similar backgrounds to socialize, play with, and meet without the fear of judgment or stigma. Lastly, the study found targeting structural barriers to be a promising approach for children with FASD. The study outlined barriers mentioned by professionals along with their suggestions on how to break them down. Overall, the study found that professionals working in this field are very devoted, passionate, and knowledgeable about supporting children with FASD. The most promising intervention for children with FASD is to provide more support to the service providers, caregivers, and children and youth by addressing the lack of funding, resources, and continuity of services they need. The interventions and approaches are there however, professionals need more ways to connect with one another to produce positive child outcomes and equitable access for families.

Keywords: fetal alcohol spectrum disorder; children; community-based programs; behaviours; inclusivity

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Correspondence: Dr. Barbara Lee
University of British Columbia, School of Social Work
Email: b.lee@ubc.ca

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability that affects the brain and body of people who were exposed to alcohol in the womb (Flannigan, Unsworth, & Harding, 2018). FASD is prevalent in 4% of the population in Canada and makes up a disproportionate number of children in need of Ministry of Child and Family Development (MCFD) assistance in British Columbia (BC). People with FASD have unique strengths and challenges and require community and family support to maintain wellbeing (Flannigan, Unsworth, & Harding, 2018). MCFD identified a need to increase support to children ages 3-12 with suspected or confirmed FASD and required more information about what interventions can be implemented to support these children.

The purpose of this research is to contribute to a collection of evidence-based interventions designed to support practitioners in delivering services to this population. The research will explore the question of what non-FASD-specific community-based programs and approaches clinicians and practitioners have been finding promising for use with children aged three to twelve years old with confirmed or suspected FASD. The research aims to collate relevant literature and reference this with the experience of practitioners in the field through focus group interviews to discover more information about promising practices for children and families with FASD. The research will explore the clinician's current practices and approaches and utilize their recommendations to advocate for improving interventions to produce positive child outcomes, early interventions, and equitable accessibility.

Literature Review

“Fetal Alcohol Spectrum Disorder (FASD) is a serious social and health problem for the child welfare, health, and education systems in North America and other parts of the world" (Fuchs et al., 2010, p.232). “FASD is a highly complex disability, intertwined with the social determinants of health and other factors which can affect people from all economic, ethnic, religious, racial, or societal backgrounds” (Flannigan et al., 2018, p. 4). The focus of this literature review will contribute to the the research proposal by exploring literature about developmental, cognitive, and behavioural manifestations and consequences for children affected by FASD. In addition, therapy programs and interventions that are efficacious in improving outcomes for children with FASD diagnosis. Interventions used for children with behavioural problems will be examined to explore for possible use for children with FASD.

The literature analysis shows that researchers have a similar opinion in defining FASD as a lifelong neurological and developmental disorder caused by prenatal alcohol exposure (Simons et al., 2018, p. 1). Coriale et al. (2017) provide a broader vision of FASD and state that “the definition, even though not exactly diagnostic, applied to the entire gamut of the negative consequences in the offspring of mothers drinking during pregnancy: physiologic, behavioural, and neurocognitive abnormalities" (p. 360).

Developmental, Cognitive, and Behavioural Consequences and Manifestations of FASD

A large body of research documents cognitive deficits and behavioural-emotional difficulties in individuals with FASD, and demonstrates that when unsupported, people with FASD are vulnerable to higher rates of health and social difficulties. According to Taylor (2021), "there are over four hundred and twenty-eight comorbid conditions linked to FASD" (p.157), and children prenatally exposed to alcohol present with a variety of physical, cognitive, and behavioural problems to varying degrees. Jacobsen et al. (2022), for instance, provide the following list of developmental and behavioural manifestations of FASD: growth delays, differences of facial features, ongoing medical problems, sleeplessness, as well as neurological disorders, and cognitive deficiencies such as problems with memory, learning, attention, and social communication (Jacobsen et al., 2022).

In addition, Taylor (2021) provides a detailed exploration of FASD manifestations in school-aged children and states that "symptom profiles of school-age children with FASD are among the best recognized and studied and form the basis of the brain domains described in most diagnostic guidelines (p. 90). Taylor (2021) further explores the cognitive and behavioural domains in school-aged children with FASD, including academic performance, memory, attention, executive functioning, communication, self-regulation, and sensorimotor functioning. School-aged children with FASD commonly experience difficulties with concentration, speed of information processing, and learning challenges in arithmetic, low average cognitive functioning, executive dysfunction, memory deficits, language and social communication impairments (Taylor, 2021). They experience difficulties with abstract thinking, atypical motor integration, and adaptive dysfunction spelling performance has also been identified as an area of impairment, with deficits in working memory contributing to these difficulties (Glass et al., 2015, as cited in Taylor, 2021). Moreover, behavioural challenges, such as impulsivity, poor executive functioning, and poor judgment, are seen in interactions with teachers and peers, and comorbid mental health challenges of attention deficit hyperactivity disorder (ADHD), mood disorders, and conduct disorders can contribute to severe challenges to group educational programming (Glass et al., 2015, as cited in Taylor, 2021).

While there is a wealth of research documenting the cognitive and behavioural difficulties of children with FASD, there is a recognized need for research that documents their strengths to balance the understanding of FASD and accurately represent individuals with the disability (Flannigan et al., 2018). From the research that has been collected, the strengths of children with FASD include their creativity, generosity, outgoing, friendly personalities, strong sense of determination, willingness to forgive and live each day as a new day, high level of empathy, and ability to care for younger children and animals (Flannigan et al., 2018). Individuals with FASD have also been found to be strong hands-on learners and can be successful in non-traditional learning environments (Flannigan et al., 2018).

Interventions Used to Treat Fetal Alcohol Spectrum Disorder in Children

This section of the literature review will examine programs and interventions that have been researched to improve outcomes of children with FASD diagnosis. The literature reviewed consistently found that interventions are most effective when they are flexible to allow for differences in individual children's strengths and needs, as well as include family support to maintain consistent care and expectations (CDC, 2022, Ordenewitz et al., 2021, Pei et al., 2021, Taylor, 2021). Interventions are shown to improve a child's condition with early intervention (CDC, 2022), and emphasized the importance of a multidisciplinary approach to the care of children with FASD, such as doctors and psychiatrists, psychologists, educational specialists, and speech and language professionals, to coordinate the care holistically (Ordenewitz et al., 2021). Individualized assessment and diagnosis are noted to be important for the holistic care coordination of these services, as well as for families and schools to have a strong understanding of the child's strengths, needs and vulnerabilities (Ordenewitz et al., 2021, Taylor, 2021). The literature identified that there is a scarcity of randomized-control trials regarding therapy for children and adolescents with FASD, especially with follow-up studies that could assess the efficacy of the intervention across different stages of development (Bertrand, 2009, Ordenewitz et al., 2021). Finally, family cohesion, stable caregivers whom children can form positive attachments with, and protective home environments are predictors of well-being for children diagnosed with FASD (Pei et al., 2021).

Family Based Interventions

Behavioural parenting training is one of the most effective ways of addressing behaviour problems among children (Bertrand, 2009). Effective intervention programs that address parents' responses to their children's behaviours, and caregiver distress are essential for the overall wellbeing of the children and their caregivers (Bertrand, 2009). The efficacy of the Families on Track Program, which has been adapted in Canada from the American Families Moving Forward Program has been well-researched and has shown promise in its ability to positively impact parenting attitudes, and improve children's emotional regulation, and self-esteem (Bertrand, 2009, Petrenko et al., 2017).

There are several other family-based programs developed which have also been identified to be beneficial (Pei, 2019, Taylor, 2021). These programs include Mindful Parenting Education, Parents and Children Together and Parents Under Pressure.

Interventions Addressing Child Executive Function

Programs that address executive functioning in children with FASD can improve behaviour, and build important life skills (Nash et al., 2015, Soh, 2015). The Alert Program is a 12-week intervention that uses the metaphor of a car engine to describe the concept of self-regulation. The program is broken down into three stages: teaching children emotional identification skills and offering children a variety of strategies to regulate and monitor their emotions (Nash et al., 2015). Parents of children reported improved emotional regulation, as well as reduced externalizing behaviour problems (Nash et al., 2015). The program has also been researched to have significantly increased frontal grey matter in children's brains (Soh, 2015), and its inclusion of parents in addressing social skills allows children to be supported at home, at school, as well as in sessions with clinicians (Soh, 2015).

Interventions Addressing Child Social Skills

Individuals with FASD can be supported in improving their social skills through intervention. The Children's Friendship Training Program is being implemented by Canadian FASD clinicians (Pei et al., 2021, Ordenewitz, 2021) and was originally developed to address the needs of children with autism spectrum disorder and attention deficit hyperactivity disorder (Laugeson et al., 2007). Adaptations were made to make the program accessible to children with FASD diagnosis including breaking the material into simpler components, increasing opportunities for exposure to and rehearsal of new material, presenting the information in multiple formats, using positive reinforcement techniques such as stickers and prizes, and individualizing the behaviour programs (Laugeson et al., 2007). Research has found that following treatment children exhibited a statistically significant increase in their social skills knowledge and improved social behaviours which were retained over the three-month follow-up period (O'Connor et al., 2006).

Interventions Not Specific with Children with FASD

There is a wealth of information regarding evidence-based interventions for children with behavioural disabilities not specific to children with FASD. There are two common types of interventions that are prevalent in the literature. Positive behavioural interventions appear to be the classic avenue for supporting children with behavioural disabilities (Einfield et al., 2013). The other stream of interventions revolves around parent-directed support programs (Einfield et al., 2013). Several empirical studies looked at the effectiveness of these interventions.

Positive Behavioral Interventions

Positive behavioural interventions (PBI) studies take heavily from Autism Spectrum Disorder (ASD) research and studies are seeking to generalize these interventions (Neil & Liesemer, 2020). In general, PBI seeks to target problem behaviours and develop skills that aid in managing the behaviours. PBIs produce generally positive outcomes for children with behavioural disabilities across all studies (Conroy et al., 2005; Einfield et al., 2013; Eldevik et al., 2010; Neil and Liesemer, 2020; Petrenko, 2013). Outcomes for these interventions all deal with reducing problem behaviours such as destructiveness and disruptiveness, and increase in adaptive skills such as engagement, social skills, and general improvements to behavioural functioning (Conroy et al., 2005; Einfiel et al., 2013; Neil and Liesemer, 2020; Petrenko, 2013).

As the studies in PBI had similar methodology, the findings all also echoed similar results and limitations. Researchers cited a lack of quality indicators such as measures of treatment integrity and replication of effect (Conroy et al., 2005; Neil & Lisemer, 2020; Petrenko, 2013). A study also found a significantly small amount of studies reported on race (Conroy et al., 2005). No other study talked about culture or gender differences and this area is largely unresearched. Small sample sizes were also a concern across the board. Overall, the research suggests that the use of PBI for children with behavioural disabilities is promising, but not without caution and further research.

Parent Training Interventions

There is an increasing amount of research done on *Parent Training Interventions* (PTI). Some of the common PTI interventions studied include *Incredible Years Parent Training* (IYPT), *Triple P* (Positive Parenting Programme) and the adapted *Stepping Stones Triple P* (SSTP), and *Signposts for Better Behavior*. The research showed that PTI had positive influences on children, either decreasing challenging behaviour or increasing alternative appropriate behaviours (Einfiel et al., 2013; Park, 2013; Petrenko, 2013; Roberts et al., 2006). In addition, PTI also had benefits of improving parental discipline style and parent-child communication (Park, 2013; Roberts et al., 2006). In terms of looking at available interventions, PTIs look promising with potentially a more holistic view of care, but have added costs and barriers not present in PBI's such as scheduling constraints with the family.

Physical Activity Interventions

Physical activity interventions also had favorable outcomes. Ash et al. (2017) looked at the effects of physical activity in lowering problem behaviours in children with behavioural disabilities. The results from this review indicate that both single bout and repeated physical activity interventions have beneficial effects. Both short and longer-term aerobic exercise of moderate-to-vigorous intensity had positive effects on areas of executive function and behavioural outcomes, suggesting that exercise may have immediate and sustained effects on specific outcomes (Ash et al., 2017). Physical activity research also has similar limitations to the others with questions of generalizability, type of studies conducted, and the driving mechanism for the positive outcomes being uncertain. The main argument against physical activity is that there is no theoretical basis for how it affects children with behavioural problems but just draws on the effects on children in general.

Overall, the literature suggests empirical backing for several interventions. PBI, PTI, and even physical activity interventions have positive effects on children with behavioural problems. The literature did contain noticeable gaps with not enough attention paid towards prevention as well as any attention paid to group interventions. Based on the existing literature, however, the work left for further research is to narrow down which of these interventions could work best for those with suspected FASD.

Literature Review Conclusion

A gap identified in the research is regarding the efficacy of interventions based on the functional needs of children with FASD. Through the collection of data from knowledgeable clinicians, evidence-based interventions to support this population will be explored in further depth. The interventions developed to address FASD, and other developmental disabilities were found to overlap in multiple areas, and the insights of clinicians connecting these interventions have not been studied. The insights of clinicians on promising approaches and interventions for children with FASD will be further explored to utilize their recommendations to improve policies and practices.

Theoretical and Conceptual Framework

Our theoretical and conceptual framework is grounded in social work theories. We draw upon *trauma informed approach*, *strength-based approach*, *systems theory*, *and positive inquiry* to guide the way we conducted the research. A *trauma informed approach* recognizes the role that trauma plays in the lives of service users and service providers (Isobel, 2021). In incorporating this with our methodology, we were cognizant in the questions we asked to ensure they would not cause undue harm or recreate traumatic experiences. *Strength-based approach* is centered around the highlighting of assets or strength a community has in order to create change (Bryant et al., 2020). This guided our view in sampling, and understanding the different capabilities service providers have in different settings and how valuable that could be in answering our research questions. *Systems theory* is useful in understanding how structures interact with one another on macro, mezzo, and micro levels (Wirth and Kleve, 2022). We used systems theory to guide our understanding of the data to ensure we would look at the research holistically. Lastly, we drew upon positive inquiry. *Positive inquiry* is an organizational change model that focuses on positive factors as a way of creating knowledge and change (Hung et al., 2018). This approach was adopted in our research through creating questions that ask about the positive experiences that service providers have regarding the topic.

Methodology

The qualitative research was conducted using online interviews and focus groups with FASD service providers to determine what programs and approaches they have found promising for children with suspected or confirmed FASD. Four individual interviews and one focus group with three participants were conducted for a total of seven participants. The seven participants consisted of three workers from MCFD, three workers from community settings, and one researcher. All the participants were located within the lower mainland region of BC. The online interviews lasted for 30 minutes each and the online focus group lasted for 60 minutes. All sessions reflected the format outlined in the data collection section within the report below, with the set semi-structured questions being asked, included in Appendix A. Each session was audio recorded through Zoom. The student researchers transcribed one interview session and the rest were sent out for professional transcription. The thematic analysis was then conducted to generate the findings discussed in the next section.

Sampling

A purposive sampling strategy was used for the study. As the research is exploratory, a purposive sample was determined to work best to select respondents that are most likely to yield appropriate and useful information (Campbell et al., 2020). Participants consisted of service providers and researchers working with children with suspected or confirmed FASD. The participants were drawn from three identified categories of professionals. The first were MCFD workers from different branches of the ministry such as Children and Youth with Support Needs (CYSN) social workers, and Child and Youth Mental Health (CYMH) clinicians. The second category of participants were workers in the community. This could include support workers in schools, community workers, occupational therapists, speech language pathologists, FASD key workers. The last category consisted of researchers from the Canada FASD Research Network (CAN FASD) and from universities conducting research on FASD. All participants had to be working in BC and have at least one year of experience working with children with FASD.

The three categories were selected as they come from different perspectives of service delivery with important insights on programs and approaches that are promising for children with FASD. MCFD workers offer a different set of approaches from community workers. Researchers also have their own knowledge base to draw from. The differences in the categories ensure a diversity in ideas of service delivery and capture the insights of service providers. The requirement for participants to have experience working with clients in BC ensured familiariarity with the service delivery systems the study seeks to serve. Furthermore, the one-year experience required ensures they have enough experience in the field to be able to contribute to the discussion.

Recruitment

Recruitment was done through facilitated contact by the research sponsor. The research team created an invitation email that the sponsor sent to prospective participants. The email contained a description of the study and the research team's contact information. The participants were asked to email the research team to signify their willingness to participate in the study. Once a member of the research team received an email from the participant, the research team emailed the participant back with a link to the demographic survey, which contained the consent form. The demographic survey asked about the participants' current position, and how many years they have worked with children with FASD. Once a participant answered the survey, they were asked about their scheduling preferences and informed when focus groups were scheduled to occur. If a participant was not able to attend a scheduled focus group session, the research team scheduled an interview with the participant at their convenience.

Data Collection

Data was collected through online interviews and focus groups facilitated on Zoom. The online method allowed participants from different regions of the province to participate at the same time (Allen, 2013). Being online also contained the added benefit of being able to control the anonymity of participants (Woodyatt et al., 2016). Additionally, Zoom also provided the safest form of gathering, given the current COVID-19 pandemic. Focus groups and interviews are also recognized as an efficient method in extracting views and experiences regarding specific topics (Woodyatt et al., 2016; Krueger and Casey, 2015; Smithson, 2000).

The research team planned to recruit three to five participants for a micro focus group. A micro focus group format was decided on for several reasons (Zuckerman-Parker and Shank, 2008). The purposive sampling ensured that the participants selected had similar roles and expertise, as such, there did not need to be a larger focus group. The smaller number also makes the focus groups more manageable to conduct and allow for more in-depth answers (Zuckerman-Parker & Shank, 2008). Additionally, by also doing interviews, the research was able to reach more participants and be as flexible as needed to ensure ease of participation. Interviews can also work well in extracting in-depth data from participants that would not be willing to share as much in a focus group. The research allows for both interviews and focus groups as both methods are qualitative and the questions asked in both methods were the same semi-structured questions, thus obtaining similar data.

The interviews and focus groups were facilitated by three student researchers who were assigned roles as the lead facilitator, note taker/observer, and technology support. Having three student facilitators promoted the smooth operation of the focus group and interviews, ensured that the data analysis was accurate, and accounted for reflexivity after the groups to increase awareness of facilitator biases (Krueger & Casey, 2015). Participants were briefed on Zoom protocols, how to use basic functions, and informed that the recording was starting. The facilitator asked seven to nine semi-structured questions in order to draw out themes regarding the topic. The questions involved asking about interventions that service providers have found promising in both children with and without FASD, outcomes of helpful programs or approaches, and what they found promising in the programs and approaches. The sessions were expected to last up to 90 minutes or less for the focus group and up to 30 minutes for interviews. The sessions were audio recorded via Zoom. The data was then transcribed by the student researchers and professional transcription services to ensure accuracy.

To mitigate possible facilitator bias, the researchers practiced reflexivity exercises. These were in the form of discussions of biases prior to the start of the focus group and interviews and in-depth debrief sessions immediately after a session concluded. In having three student researchers, the team held each other accountable in identifying and minimizing possible biases. Another challenge is that participants can be uncooperative, get sidetracked, or one voice can dominate the discussion (Smithson, 2000). The student researchers completed trial runs and practiced sessions to be able to recognize when the above concerns are occurring, and prepared strategies to mitigate them (Smithson, 2000). The careful sampling of participants also served to increase the validity of the data. The purposive sampling ensured that participants are all professionals in the same field and have similar lines of work. As such, participants can be critical of one another's answers and share their own views if they are opposed during the focus group.

Method of Analysis

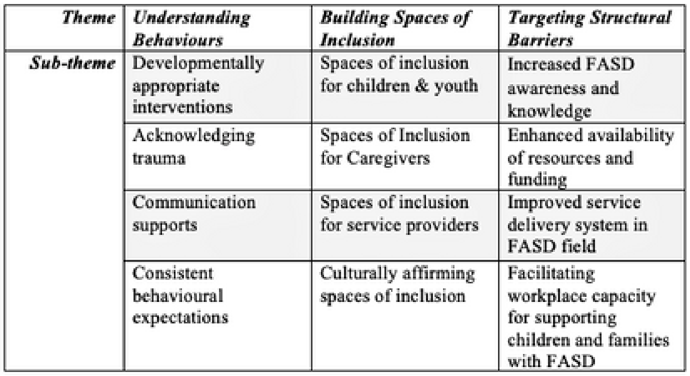
The data gathered from the focus group and interviews were analyzed through a thematic analysis. Thematic analysis offered an accessible and flexible form of analysis to draw out themes explored by the research question (Nowell et al., 2017). It also allowed for the examination of the different perspectives of research participants, highlighting similarities and differences, and generating unanticipated insights (Nowell et al., 2017). Researchers went over each transcript line-by-line, creating descriptive codes to group similar ideas from the data together. After an initial round of coding, the group discussed the codes to reach a consensus. Using the agreed upon initial codes, a second round of line-by-line coding was carried out to further group concepts together. After a third round of coding, patterns were identified in the codes in order to draw out themes. To ensure the reliability of the analysis, at least two student researchers went through the coding process for each transcript and the research team discussed the codes until consensus was reached. The themes drawn out were then analyzed and referenced against the literature to generate discussion.

Findings

Through the thematic analysis of focus group and interview transcripts, three overarching themes for working with children with suspected or confirmed

FASD emerged from the data. The three themes include understanding children’s behaviours, building spaces of inclusion for children, and targeting structural barriers that impact child outcomes. These themes were found to overlap, and interact with one another, and build upon community, family and educational support to improve child well-being. These themes were informed by both the participant’s perspectives on what interventions, approaches, and services they find positively support children’s wellbeing, and deficiencies they have noticed that create barriers to children’s healthy development. Table 1 demonstrates how the main themes relate to the 12 sub-themes that were identified during the analysis process. The results focus on the three overarching themes with a brief discussion of their respective sub-themes.

***Table 1*. The three overarching themes & their relationship to sub-themes**



Theme	*Understanding Behaviours*	*Building Spaces of Inclusion*	*Targeting Structural Barriers*
Sub-theme	Developmentally appropriate interventions	Spaces of inclusion for children & youth	Increased FASD awareness and knowledge
	Acknowledging trauma	Spaces of Inclusion for Caregivers	Enhanced availability of resources and funding
	Communication supports	Spaces of inclusion for service providers	Improved service delivery system in FASD field
	Consistent behavioural expectations	Culturally affirming spaces of inclusion	Facilitating workplace capacity for supporting children and families with FASD

Theme 1: Understanding Behaviours

Interview and focus group participants shared that stigma, lack of awareness and education prevents practitioners from accurately assessing children’s capacities and behaviours which they noted can cause children to get left behind in educational settings, excluded from services, and can destabilize families and children’s housing placements. The importance for caregivers, service providers, and schools to have adequate education about FASD , the developmental strengths and needs of the child, and the use of evidence-based frameworks to inform their interventions was emphasized throughout the data.

Developmentally Appropriate Interventions. Practitioners explained the importance of ensuring that the “*intervention is informed by where [the child] is developmentally. And using their developmental level to inform our decision making*." One participant explained that "*a lot of people that come on board end up causing more harm than good just because they're not educated on what it's like to have FASD, how it impacts the brain, how it impacts functioning*." Specifically, participants shared how a developmental perspective informs assessments and interventions and prevents practitioners from giving children stigmatizing labels related to non-compliance. "*And then also shifting the child won't do this to probably that child can't do it. I think a lot of people think that “Oh, he's purposely not doing the activity”, but it's that they actually do not have the capacity to*". Another participant discussed that education about FASD is necessary for workers in a variety of social service environments, rather than just in FASD specific services. “*I've worked with people who work on the frontlines for housing and they often aren't trained in FASD. So if they're trying to house somebody with FASD, and they're getting frustrated because it looks like they're not wanting to do what they need to, they're not complying. But really, it's more of a capacity and understanding that's missing.*”

The frameworks that practitioners stated informed their approaches included a functional behavioural approach, developmental perspective, strengths-based approach, and the towards healthy outcomes framework, developed by CanFASD. When working directly with children, the following practices for supporting children to learn in an encouraging and validating way were mentioned; prompting, redirecting, reminding, showing/modelling, rewarding positive behaviour, imposing consequences that match the child's capacity for associating cause and effect, and providing opportunities for success and confidence.

Acknowledging Trauma. The importance of employing a trauma-informed approach when working with children with suspected or confirmed FASD was emphasized by participants. Participants, specifically from mental health services and research organizations, stated that it is common for trauma symptoms to overlap with children’s emotional regulation capacities, which require support and acknowledgement for effective interventions. "*It is such a complex diagnosis that's so closely linked to trauma. So, I think that that is huge as* *well. Ultimately, it's sad to say, but there's just not enough support.*" Participants discussed trauma and mental health support to be a concerning unmet need for children with FASD, and discussed how eligibility criteria contributes to children with FASD being excluded from accessing supports. "*I think a lot of folks that are in this field think that FASD makes children not capable of attending our services or accessing mental health due to capacity issues. But I think that as FASD and trauma are so closely linked, there's a lot of similarities between the two that overlap.*" Participants discussed that when behavioural interventions are trauma-informed, they can better understand the child and work towards their goals. "*I think that typically the goals are to help the youth find a baseline and working with emotional regulation pieces. I know that mental health contributes to behavioural issues in school or in their community or their lives or anything like that. So I do find that goals in mental health specifically, are helping with emotional regulation pieces.*"

Communication Supports. Supporting children with communication through visuals, art, picture exchange communication systems, sign language, and speech therapy was said to be important for positive outcomes and reducing behavioural challenges. "*Kids have behaviours because oftentimes they can't express themselves. So being able to equip the child with the skillset to communicate and to learn the verbal piece.*" The role of Speech Language Pathologists in supporting children to build communication skills was stated to be an important intervention for improving child well-being. "*The Speech Language Pathologists encourage the child, whether it's using a mix of words, short sentences, to maybe even adding some sign language on top of that. So that they can communicate rather than lashing out at parents or other people or going into withdraw mode because they're so detached – they're just thinking like others just can't understand me and they just go into a shutdown mode. So again, really helping the child to express themselves, and to share to what they want and need.*"

Consistent Behavioural Expectations. Professionals shared the importance of having coordinated care between service providers, schools, and families so the child has consistent behavioural expectations that they can learn to follow. "*Because I find that if you do something differently in school than you do at home, then that's where a blow-up happens, either at home or at school. So I think consistency across the board, one-on-one support, but also in collaboration with all the service providers together.*" Participants stated they found that children are not set up for success if behavioural supports are not communicated with families or other systems they interact with, and how this can trigger outbursts, destabilize families or housing placements, and impact child mental health.

Theme 2: Building Spaces of Inclusion

From the responses in our data, spaces of inclusion mean having a physical, virtual, or metaphorical space where youth, parents, and service providers can connect and for people with similar backgrounds to socialize, play with, and meet without the fear of judgment or stigma. A core theme of the responses we received was how key it was for children to be able to support one another, and for service users to be able to connect and coordinate. In speaking about spaces of inclusion, there were four main divisions in the data. These are spaces of inclusion for children, for caregivers, for service providers, and for culture.

Spaces of Inclusion: For Youth. According to the participants, socialization and inclusion for youth means youth being in school, being with other children their age, and learning social cues and norms from being around them. As one participant says, "*They see their friends, they observe and I just – when I see that, I think 'monkey see, monkey do'. It will never get old. You see his friends go and grab the launch box. And I don't need to say, he's observing.... So that's why inclusion to me is one of the best ideas*". Another point to come out from the data is having activities that youth can fully participate in and not feel different. Particularly any fun physical or artistic activities. "*I build pinatas with two of my kids.... I didn't know that FASD was such a thing.... And when we built the pinatas, I noticed that they were like so into it. Like "I can do this, I got this. This is my glue, and this is where it goes. And I want to start right here because that's the way my pinata is going to look.*". Some participants also found it helpful to have spaces for kids to be able to socialize with children with FASD like them as it can be empowering for them to help their peers. *"More safe spaces and more spaces for them to kind of meet up with other people in their similar age and situation to kind of share and talk about how they can be better amongst themselves."*.

Spaces of Inclusion: For Caregivers. For caregivers, participants mentioned the stigma that comes with parenting a child with FASD. They found that it is important to address these feelings in a non-judgmental setting. *"Expressing grief about the situation with the family, parents being able to express all those feelings in a non-judgmental environment*". Another way mentioned by participants is to foster connections with other parents through groups. *"I would say support groups probably would be a really huge piece for parents, whether it's a women's support group, and then there's of course those single dads that are out there – so a single men's support group would probably be a really important piece for supporting their mental health. And just really an emotional support network that could be available to them"*. Not only were parent groups found useful for emotional support but also as a way for caregivers to share resources and empower each other. As another participant says *"it's a single dad and that person went to men's support group. That was his way to get networking connection with others and also kind of a place to, I guess, vent for any frustrations or worries that they may have. And that would also be an opportunity for other dads that may be able to offer some recommendations, and also the dad probably also feels empowered because he may know something that other people don't."*. Lastly, another participant noted that these spaces can also occur online. *"And I think, Facebook, I think there's some parenting Facebook groups out there that really help"*.

Spaces of Inclusion: For Service Providers. A recurring notion from the participants is that FASD service providers need ways to connect with one another. One participant expressed a need to coordinate in order to share their different expertise. "*I'm not an expert in family counselling, or even OT, SLP and PT, so just really leading onto each other's professional strength. And have that constant communication can be helpful.*" Participants also see constant communication as something that can improve services. "*a regular meeting that goes on for the care team is often very helpful.... I find that having consistent communication and open transparent communication and how to continue support for the family would be really important*". Focus group participants also found the focus group itself to be useful in sharing knowledge. "*I'm really interested to hear the results of your research. And I hope that there are other focus groups that have other people who can bring forward things that are working really well that we could try to incorporate and just have more knowledge of things that work.*" Lastly, a participant mentioned that service providers are very engaged in their work and that advocacy has been increasing. As one participant says "*people from the community are getting more and more involved. And there's more and more advocacy happening, which I think is really great*".

Spaces of Inclusion: For Culture. Participants shared that having spaces where children can express and explore their culture can be meaningful intervention. One participant provided an example about Indigenous families. "*I guess from a cultural perspective, I mean besides that sometimes families, they really rely on like support of their own culture, right. Especially say I will give an example that maybe this is a child who's Indigenous, right? The child and the family can benefit from attending an Indigenous-based support service*.". In speaking about culture, another participant commented on how important it can be saying that "*it's a part of the child's life and it's important to be a part of that.... And really just for the kid to understand their ancestry and roots and so forth.*". Participants pointed towards culture as a possible protective factor for children and their families.

Theme 3: Targeting Structural Barriers

The third theme identified during interviews with practitioners was targeting structural barriers. Many practitioners noted that the system has multiple limitations making service provision in the FASD field extremely challenging. Additionally, many practitioners reported that not only service providers but also children and their families are significantly affected by systemic barriers and limitations.

Increased FASD Awareness and Knowledge. Most participants mentioned the lack of knowledge and awareness of FASD as a significant problem affecting society in general, service providers working in the field, and caregivers supporting children with FASD. The following barriers in this area have been identified by practitioners: stigmatization of FASD, lack of knowledge and understanding of FASD, lack of education and training in the field, and lack of knowledge exchange. *"But generally speaking, I think with my work, the overall goal of FASD community, in general, is for there to be greater understanding about FASD, within society at large, within Canada, and for other clinicians as well. I think it's not an area that gets a lot of training focused on it. So for practitioners, for physicians, I think, overall, the goal is just a greater understanding and awareness."*

Participants voiced the following recommendations targeting the above-mentioned structural barriers: raising FASD awareness, more training, educational programs, and resources for service providers, children, and families, and professional collaboration and connection to other service providers. "*I think as part of education and training and if there are opportunities to have more of these workshops and training that can help – and I can only speak on myself from CYSN perspective, I personally would love to be in one of those workshops, if there is more available, that really talks about how to support families with FASD.*"

Enhanced Availability of Resources and Funding. During the interviews, many participants shared their concerns about the availability of resources and funding for children, their caregivers, and service providers. The following structural barriers in this area have been identified: lack of resources, supports, and funding for children with FASD, their caregivers, and service providers, and lack of stable housing for children and families.

“And I think that with FASD, the funding is skewed as well when it comes to the Ministry, because they do so much for physical disabilities. You get so many supports for children with physical disabilities, but not for FASD.”

“Working with kids and the experience that I have, money is a big thing in families with kids, especially all types of special needs.”

Most participants recommended making supports and resources more available by increasing funding for FASD-specific programs, services, FASD key workers, and children and families. *“You don't get one on one workers any longer. It is just too much for the financial burden of the education system. The School Boards need to get on board with this; then, the parent advisory committee needs to get on board with this. There are several external sources that need to get on board with our MLAs and our upper government in Canada. They need to be more aware of what's going on in our school systems and why."*

Improved Service Delivery System in FASD Field. According to the respondents, there are a lot of barriers in the FASD service provision system itself: lack of focus on FASD service delivery, not enough services in the FASD community, lack of respite and specific individualized services, exclusion from services due to service eligibility criteria, long waiting lists, and inequality of services as a result of lack of supports and services in remote and rural areas.

"*I just think there's not enough service delivery. There's not enough psychiatric support. There's not enough external, child, family services support. They're burning out rapidly. They don't have that availability, or ability to work with the children once they place them in a foster home. If they end up going into care, they are too overwhelmed with all the cases they have. There's just too many children in care for them to do a really good check in process.*"

"For me, a challenge that I've noticed is I'm in a fairly rural area, and just the availability of services is very challenging. There's not a lot in terms of respite availability. I know there's a massive level of work for MCFD and CYMH in our area. So, it's hard to have the needs met because we just don't have enough services relative to the number of needs that we have in my area."

The following recommendations targeting the above-mentioned structural barriers in the service area have been identified during the sessions: addressing gaps in services and adding more supports in the community, more individualized programs, increased access to behavioral supports, mental health services, and services for caregivers of children with FASD, more services in geographically remote and rural areas, and advocacy for more opportunities and inclusion.

“And I also think that other local programs that would be very successful are outreach programs that are in

satellite offices in the communities as well. I think that's very, very important, because not everybody can make it to Vancouver. The bigger cities are great, and they have all these great opportunities, but sometimes some of the smaller, outreaching cities don't have that type of services."

"But when you have a lot of families that may have kids with FASD, the other question is, is there even enough service providers in the community that can actually offer it? And if so, how long of a wait is it going to take, right? If it's going to be – is there something that can be met within a month's time, or are we looking at three months, six months, or even longer."

Facilitating Workplace Capacity for Supporting Children and Families with FASD. Many practitioners voiced their concerns regarding professional workplace barriers that affect their capacity to provide quality services for children and families with FASD: lack of peer support and collaboration between professionals, lack of staff, huge workload and burnout, and difficulties with staff retention. "*And then, as well as workers being so overwhelmed, they may get a stack of applications, and then sometimes they miss the application. I think that's a sad situation when it comes to children that might get missed as well.*"

The recommendations targeting professional barriers included enhanced availability of resources for service providers, professional collaboration and connection to other service providers, attracting more professional staff, and facilitating staff retention.

"*I'd say staffing and workload probably would be the key thing. As you know in the helping human profession and whether social work, or even FASD Key Workers, I would say that staffing's always going to be one of those things and workload issues. I would imagine that as an FASD Key Worker there's probably a lot of families under their belt and there's not that many staff – so staffing definitely would be a huge piece. And retaining the staff in the workplace. And then I guess for me from Child and Youth Support Needs, the Department's perspective would be looking at the future of eligibility of service framework."*

Discussion

The data and findings of the research complement the literature, as the importance of flexibility in addressing individual children's needs, family involvement, early intervention, and a multidisciplinary holistic approach to care coordination were emphasized throughout both methods of data collection. The structural barriers identified in the research findings are considered new data due to the scope and focus of the literature review that was completed.

Interventions to support child executive functioning were found to reduce child emotional outbursts, increase self-esteem, and self-confidence, and help to build essential life skills, such as emotional identification and regulation. Participants suggested specific programs and approaches addressing FASD-related child executive functioning, such as skills teaching programs, facilitated adaptive and goal-based behavioural support, prompting, immediate rewards, redirecting, and having lots of structure and routines. *"Having a behavioural interventionist that is involved, and looking at what are the behavioural methods that are goal-based and also that can support the child."* One of the program examples provided by participants is Towards Healthy Outcomes. *"It's a really great framework that lets us really consider the whole person. It's a little bit more person-centered and holistic. So we consider strengths with that. It allows us the opportunity to think about developmental lifespan perspective. And it also gives us some place to think about the little systems play in the lives of people with FASD."*

Interventions addressing child social skills were identified to be benefit to children with FASD and improve their social behaviors in both the literature, and the research data. Practitioners in the field advised socialization programs in schools, joint social activities for children and their parents, Friendship Centers, and support groups as key components of building socialization skills. *"I think that in terms of any of the programming obviously socialization for a lot of these kiddos is important. Learning those socialization skills,* *also being able to observe others and see what do cues look like.”*

Additionally, our research supports the literature review findings around the importance and benefits of physical activity interventions for children with FASD. Several interview participants stated that physical and aerobic activities are very beneficial in addressing developmental and behavioral limitations for children with FASD. "*So that's something that I think needs to be enhanced a bit more is that they need to have those opportunities for those children that have that extra energy to get out and just go, you know. Get that exercise. Go, go, do a couple of laps, and come back to class and not let it be a disruption*." Practitioners advised that school outdoor activities, balancing board programs, and skateboarding programs are very effective for children with FASD.

The research and literature showed that family-based interventions and parenting training are essential for children with FASD and their families to have a sense of stability. "*The family programs offer that external help while the parent is in the program. So that's very important.*" Participants suggested the following family-based and parenting training programs for FASD children and their caregivers: Jordan's Principal funding, respite programs, allowing parents to have a break and take some rest, the Head Start program, which educates children and their parents, Zajak Ranch for children, parental support groups, and culturally based family supports. One participant discussed the value for parents in accessing education and support “*So again, it’s an exchange of information and feeling the sense of belonging when they’re already feeling a little bit isolated. So hopefully these will bridge, and provide a little bit of that relationship, so they feel they’re part of a group that understands them.*”

Discussion of Additional Findings

The focus of the research was to develop a collection of evidence-based interventions to support MCFD’s policy development for children with suspected and confirmed FASD, and thus the literature reviewed had a focus on programming, interventions, and their efficacy. The data we collected from participants highlighted that the structural barriers reflected in the findings impact the child outcomes and goals of services such as family stability, self-esteem, emotional regulation, and independence, that community-based programming seeks to meet. Furthermore, while the literature emphasized the importance of a multi-disciplinary approach to services, participants discussed how the current service delivery model creates a lack of continuity of care and impacts their intervention’s efficacy in practice. The data also reflected that staffing shortages, high caseloads and burnout impacted the capacity of service providers in community services and schools to provide the level of support needed for the programs to improve child outcomes and intervention goals. This was not reflected in the literature review as the research collected information about the efficacy of programming in controlled research setting and did not account for limitations in service provider capacity in their studies.

Lastly, participants shared that they felt that they lacked knowledge about best practices for working with children with suspected or confirmed FASD, as well as interventions that are promising in addressing the children’s needs. Through the review of literature, there appeared to be a wealth of information about efficacious interventions, and best-practices to support children with FASD. The data analysis shows that there is a disconnect between the knowledge base of practitioners, and information available. Participants stated there is a need for resource guides and training about FASD-specific services and how to modify non-FASD-specific services to support children. It can be inferred that the lack of funding and availability of services also impacted the participants' lack of knowledge of available resources.

Limitations

Several limitations can be found within the study. The first is through the purposive sampling. The selection process involved in purposive sampling is prone to researcher bias to determine whose voices can be heard (Campbell et al., 2020). To this extent the research team recognizes that service users and Indigenous people have not been factored in. As the research is exploratory, it was outside of our scope to fully consider all populations and prepare to interview service users. Due to the need for careful considerations in ensuring good practices for service users and Indigenous peoples, the time limited nature of the research project did not allow for time to include these perspectives to the scope of the project. It is important to consider this limitation when attempting to use the study to inform practice. Another limitation is from the qualitative nature of the study. The answers come from the participants' perspectives and are subjective, which might not be applicable in other contexts. The focus group is also susceptible to facilitator bias and group think even with measures in place to negate this (Smithson, 2000). Lastly, thematic analysis is also subjective, and data can be missed (Nowell et al., 2017). As student researchers, we acknowledge that there could be multiple ways to interpret the data.

Implications and Recommendations

In analyzing the data, some recommendations have come out from the study. The first is to create spaces for caregivers and children with FASD to meet and support each other. Socialization has been identified as a way for parents to exchange their techniques and to empower each other. The same is true for children in school settings. Participants identified this as a way to help families feel included. The second recommendation that participants ask for is to re-examine funding practices and priorities toward the needs of children with FASD. The lack of resources has been cited as a major barrier that practitioners have in administering these programs and having more set aside for children with FASD can go a long way. The last recommendation is to promote connections between service providers and encourage more professional collaborations. Participants expressed wanting more training and interdisciplinary meetings as continuity of care has been one of the biggest gaps they spoke about. Ensuring care teams and families are on the same page can go a long way in improving the experiences of children with FASD.

What we have found in conducting this study is that there is already a wide base of knowledge on interventions and approaches for children with FASD. The gap identified from speaking to professionals is that this knowledge is not widely shared or accessible, and even professionals feel isolated in delivering services to children. We recommend further research into into knowledge mobilization, and in understanding how to connect services together as a direction for MCFD to take to further improve service delivery. The FASD community has many strengths to tap into as noted above and learning more about how to unlock their full potential can be promising in improving outcomes for children with FASD.

Conclusion

FASD is a lifelong disability and people with FASD have unique strengths and challenges that require holistic support from their family and communities. MCFD has identified a need to learn more about best practices for working with this population in order to expand their service delivery. This study aims to answer the question: what non-FASD-specific community-based programs and approaches have clinicians been finding promising for use with children with confirmed or suspected FASD? To do so, a focus group and interviews were conducted with professionals working with children with FASD. Professionals were recruited from MCFD, community organizations, and researchers to collate their perspectives on promising interventions and approaches. The 3 themes identified from the interviews and focus group are understanding behaviours, creating spaces of inclusion, and targeting structural barriers.

In interviewing and speaking to professionals working with children with FASD, we have found that they are already knowledgeable in supporting these children and families. Most of the answers they provided were congruent with the information found in the literature review. What professionals identified as an area they need support with the most is in addressing structural barriers, increasing awareness and education on FASD, and fostering connections between service providers among each other, and with families, to ensure the continuity of care for children with FASD.

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Appendix A: Focus Group & Interview Protocol

1.What goals do FASD services typically look to achieve? How do you know an intervention has been positive?

2.What unmet needs by children with confirmed or suspected FASD have you noticed from the current service delivery model?

3.What programs are used specifically for children with FASD? Which programs do you find to be promising? How would these programs be generalized for children with suspected FASD?

4.What approaches are used specifically for children with FASD? Which approaches do you find to be promising? How would these approaches be generalized for children with suspected FASD?

5.What programs that are not FASD focused do you see children with FASD accessing?

6.Which of these non-FASD focused programs do you find promising?

7.What aspects of the non-FASD focused programs did you find promising?

8.What else would you like to add to the discussion?