

**What I Want My Teachers to Know:
The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder**

by

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in

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts resulting from alcohol exposure during prenatal development. Individuals with FASD have strengths they can use in and out of the classroom, yet much of the current FASD literature has largely focused on personal deficiencies such as deficits in thinking abilities, and challenges with behavioural functioning and emotional regulation. This study employed a qualitative descriptive design. Semi-structured interviews approximately 30 minutes in length were conducted with two adolescents from Alberta, ages 13 and 15, with FASD. These adolescents voiced what they wanted teachers to know about their perceived strengths and struggles across school, home, and community settings. Interviews were audio recorded using Google Meet, transcribed, and analyzed using thematic analysis. Interview data provided insight into lived experiences including the strengths adolescents with FASD have and the struggles they experience in and out of school settings. By engaging individuals with lived experiences, more can be learned about the unique perspectives of adolescents with FASD. Results revealed adolescents with FASD want teachers to know (1) they are aware of some ways to manage their emotions and some of what adds to their struggles, (2) they have preferences for the ways they learn, and (3) they value and desire meaningful relationships. These findings provide insight into how teachers can position themselves to provide high-quality instruction and specialized support for adolescents with FASD and appreciate the unique strengths and interests adolescents with FASD have to offer.

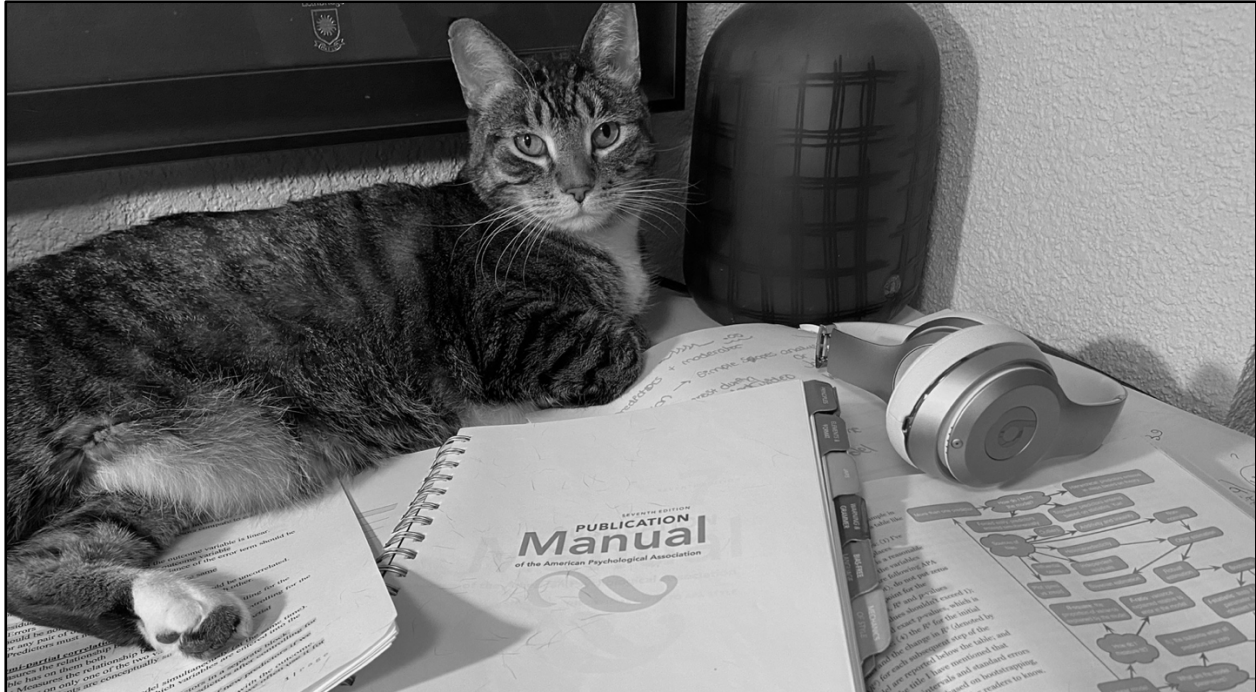
Keywords: Fetal Alcohol Spectrum Disorder, strengths, struggles, teachers, adolescents, lived experiences

Preface

This thesis is an original work by Vanessa Catherine Boila. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board 2, Project Name "WHAT I WANT MY TEACHERS TO KNOW: THE LIVED EXPERIENCES OF ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER", No. Pro00105221, JANUARY 29th, 2021.

Dedication

This thesis is dedicated to my cat, Philly. Thank you, Philly, for being a dedicated student during the pandemic. Thanks for attending classes with me when they were delivered on Zoom and making these classes more exciting for myself and my classmates. I always knew you were a smart cat, but now I know you are more knowledgeable than before.



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What I Want My Teachers to Know:

The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder

Chapter 1: Introduction

Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) describes a range of “mental and physical disabilities” resulting from in utero alcohol exposure during pregnancy (Brown et al., 2019, p. 165). FASD, considered a life-long disorder (Centres for Disease Control and Prevention [CDC], 2022), can affect anyone irrespective of educational achievements, social class, or ethnic background (Lange et al., 2017). According to Popova et al. (2019), FASD affects 2–3% of Canadians, more than the percentage of Canadians affected by other developmental disabilities such as autism spectrum disorder, Down’s syndrome, and spina bifida.

Identifying FASD has an “educational advantage” because diagnostic and assessment information may help professionals provide targeted support in areas individuals with FASD are known to struggle (Blackburn et al., 2012, p. 58). However, many of the complexities associated with FASD may make it harder to attain shared understandings to create this educational advantage. These complexities can include funding instability (Clarren et al., 2011), the stigma children with FASD and their families experience (Bell et al., 2016), and a high presence of mental health challenges in this population (Pei et al., 2011). As well, FASD researchers have more frequently documented deficits compared to strengths (Kully-Martens et al., 2022), so understanding how to foster positive educational experiences or outcomes in this population is not always easy. Taken together, individuals with FASD may not get the support needed to experience success at school or outside of the classroom.

Exploring FASD, the Education System, and a Balanced Approach

To date, much FASD research has focused on deficits and struggles (Brenna et al., 2017), but a shift in perspective is beginning. Instead of focusing solely on deficits, personal strengths are beginning to be recognized, including balancing understandings between strengths and

struggles (Flannigan et al., 2021a). Flannigan et al.'s (2021a) study represents one of the first attempts to synthesize literature on the strengths (i.e., personal characteristics such as self-awareness, skills such as excelling at video games, and support from others such as teachers, family, and friends who are situated in various environments like the school or home) individuals with FASD have across all age demographics, from children to adults.

Blackburn et al. (2010) state teachers' roles in the classroom include addressing the learning needs of children with FASD and unearthing the unique strengths of others. To ensure positive educational outcomes for children and adolescents with FASD it is important to understand their learning profile (i.e., a range of neurocognitive abilities) (Boys et al., 2016), and design interventions that consider strengths they have and struggles they experience (Petrenko, 2015), so supports such as targeted interventions can be delivered before difficulties arise (Boys et al., 2016). Importantly, the educational environment provides an opportunity and place for understanding areas of strengths individuals with FASD have that are accompanied by a balanced understanding of their struggles.

Appreciating Strengths

Some personal strengths and specialized skills have been noted in this population, underscoring the call for more dedicated inquiry to identify personal resources to leverage in pursuit of school success. In pursuit of this inquiry, it is important to remember everyone with FASD has a unique pattern of strengths (Petrenko, 2015). Duquette et al. (2006) and Duquette et al. (2007) reveal adolescents and some young adults with FASD excel at experiential and applied activities such as the arts or athletics. Stade et al. (2011) echo this, saying children and adolescents with FASD use artistic or athletic strengths to cope with struggles such as distractibility and difficulties with concentration. Sanders and Buck (2010) also identified arts, music, and sports as areas of strength for children, adolescents, and young adults with FASD, and explained this population can persist with difficult tasks, enjoys lifting people's mood, is kind and loyal, and readily forgives others. Individuals with FASD, including adolescents and young

adults in their early 20s, demonstrate even more personal strengths such as captivating personalities (Blackburn et al., 2012), resilience (Rogers et al., 2013), linguistic diversity (Kippin et al., 2018), and optimism toward the future (Mariasine et al., 2014). Children, adolescents, and young adults with FASD have a broad set of personal strengths. These strengths provide a foundation teachers can build on to personalize learning (Blackburn et al., 2012).

Environments that are well-suited to individuals with FASD can also contribute to the success this population experiences. According to Boys et al. (2016), when teachers make environmental modifications within the classroom individuals with FASD can employ their strengths more than their weaknesses. More precisely, children with FASD excel when their educational environments have consistency and routine (Timler & Olswang, 2001). The children, adolescents, and young adults with FASD who experience the greatest success in school are those with access to specialized support due, in part, to receiving a diagnosis and who have empathetic teachers or caregivers that advocate for them (Duquette & Stodel, 2005). All in all, the context of an environment, including the people found within these environments, play an important role in developing strengths.

Acknowledging Struggles

All individuals with FASD experience impairment, including dysfunction in the central nervous system (Centre for Addiction and Mental Health [CAMH], 2022), and these impairments exist on a continuum (Millans, 2015). Individuals with FASD can experience cognitive impairments that include memory and attentional difficulties, such as trouble attending to directions, and difficulty with reasoning and understanding behaviour-consequence relationships as well as behavioral challenges (Wozniak et al., 2019). Individuals who have been prenatally exposed to alcohol may also display overly active behaviour (Kable et al., 2016). Some adolescents with FASD also struggle with self-regulation, which may lead to unlawful or inappropriate behaviour (Brown et al., 2012), and individuals with FASD are at-risk for school suspension, expulsion, or even dropout (Streissguth et al., 2004). Spanning from childhood to

adulthood, difficulties with controlling impulses, solving problems, and pre-planning, which are struggles associated with executive functioning, are other challenges this population experiences (McLachlan et al., 2020). Ultimately, these examples provide a glimpse into the many challenges associated with FASD.

FASD can also lead to social and emotional difficulties (Duquette et al., 2006). Wilhoit et al. (2017) explain individuals with FASD often find making and keeping friends challenging, especially because they have unique ways of interacting, such as being excessively friendly, which is not always appropriate in social settings. Their unique ways of interacting could result in being the target of bullying and its undesirable effects (Wilhoit et al., 2017), or being exploited by peers (Sanders & Buck, 2010). In short, difficulty with socialization or unique forms of self-expression can lead to negative, not positive, experiences.

The struggles some individuals with FASD experience may go unnoticed until school age, a time of increased demands on attentional, motor, sensory, and communication abilities, and when more emphasis is placed on understanding connections between actions and consequences (Canada FASD Research Network [CanFASD], 2019). Some children with FASD do not show visible signs of impairment, and if their learning needs go unnoticed, they may be inadequately accommodated (Blackburn et al., 2010). Without targeted educational services, children and adolescents with FASD are at risk for poor academic performance (Popova et al., 2016a), so there are some benefits to acknowledging their struggles.

As for teachers responsible for teaching children and adolescents with FASD, only occasional, specialized support is available to them in their classrooms (Dybdahl & Ryan, 2009). Making teaching even more challenging is the fact no blanket approach works for teaching all adolescents with FASD (Cleversey et al., 2018), and having diagnostic knowledge about FASD is insufficient for teachers to meet all their students' needs (Cleversey et al., 2018). As a result, when tasked with teaching children or adolescents with FASD, teachers could easily find themselves overwhelmed by all they are expected to know and do.

Unpacking Teachers' Knowledge and Understanding of FASD

In the classroom, awareness of a child or adolescent's FASD diagnosis and learning profile can help teachers better understand FASD to employ effective interventions for this unique population (Boys et al., 2016), but leveraging strengths and responding to struggles requires knowledge and understanding—what Bashista (2022) says many professionals lack. Poth et al. (2014) suggest meeting the needs of children and adolescents with FASD presents a challenge for teachers and other professionals tasked with working with them, such as educational assistants or principals, because they lack awareness of FASD and strategies to use with this population. One parent's self-reflection highlights the extensive lack of knowledge and misunderstanding of FASD amongst teachers and other professionals:

We saw pediatricians, family practice physicians, child psychologists, child psychiatrists, family therapists, occupational therapists, a whole team of developmental pediatricians and PhDs in child development, learning specialists, school psychologists, neuropsychologists, special educators, and others—all of whom a struggling parent would think would know something about FASD, but who didn't (p. 1, Bashista, 2022).

Parents/Caregivers

Parents and caregivers believe teachers are insufficiently educated about FASD. According to The Alberta FASD Cross Ministry Committee (2020), 57% of caregivers believe teachers are ill-informed about FASD. In Petrenko et al.'s (2014) study, parents of children and adolescents with FASD reported individuals who work with FASD populations, such as service providers including doctors, teachers, and social workers, require greater knowledge and understanding of FASD. The parents indicated their frustration because they felt they were responsible for teaching teachers about FASD because most of the teachers they encountered lacked knowledge about the disorder (Petrenko et al., 2014).

Researchers

Researchers such as Millar et al. (2017) note as the number of children and adolescents diagnosed with FASD increases, the need to equip teachers with FASD-suitable classroom strategies also increases. However, pre-service teachers lack sufficient knowledge of FASD, which hinders their ability to effectively meet children and adolescents' educational needs upon entry to the profession (Pei et al., 2015), and nearly 80% of early childhood educators have minimal or no familiarity with FASD (Blackburn, 2009, as cited in Poth et al., 2014). What is more, little guidance has been provided to teachers about best teaching practices for FASD (Carpenter, 2011), providing more evidence teachers lack a comprehensive understanding of FASD and strategies to use in the classroom.

Adolescents and Young Adults with FASD

Adolescents and young adults with FASD are concerned about teachers' lack of FASD knowledge and understanding too. An adolescent with FASD said teachers are not adequately trained for assisting them in the classroom, and teachers lack strategies for working with adolescents with FASD (Lutherwood, 2021). In a case study by Brenna et al. (2017), a 21-year-old with FASD revealed teachers need to increase their familiarity with FASD and all it entails. Thus, parents, caregivers, and researchers are not the only individuals to notice teachers' lack of knowledge and understanding of FASD.

Examining the Lack of Adolescent Lived Experiences

Lynch et al. (2015) says there are a plethora of studies focusing on children who have been prenatally exposed to alcohol, yet McLachlan et al. (2020) report that few empirical studies have explored the needs of adolescents with FASD and the difficulties they experience in the education system. Researchers have identified the need for more research related to the lived experiences of children and adolescents with FASD (Flannigan et al., 2021a; Skorka et al., 2020). To begin to address this gap, Skorka et al. (2022) interviewed four adolescents with FASD about their strengths and struggles as they relate to daily living. They found adolescents

with FASD experience mental health challenges (e.g., high anxiety), and emotional challenges, (e.g., difficulty regulating emotions), which hinders their ability to function independently; however, by integrating their strengths into everyday activities, their anxiety is reduced and participation in activities enhanced (Skorka et al., 2022). The present study is designed to build on this emerging branch of research.

Contextualizing the Research and Its Importance

One of the most important topics researchers can investigate is enhancing the education of anyone who cares for or works with individuals with FASD from children to adults (Bashista, 2022). Just as understanding adverse experiences associated with living with FASD or prenatal alcohol exposure can facilitate implementation of support to improve outcomes (Flannigan et al., 2021b), understanding strengths of adolescents with FASD reveals resources to leverage within intervention initiatives (Skorka et al., 2022). If teachers obtain knowledge of FASD, including learning how living with FASD affects adolescents across settings, they may be better positioned to adjust their teaching approach and implement well-suited supports and leverage the strengths adolescents with FASD have. Additionally, by obtaining first-hand perspectives from adolescents with FASD, it is possible to highlight the value of their experiences and address a gap in the literature. As another benefit, few studies on the educational needs of adolescents with FASD have been conducted in Canada (Cleversey et al., 2018) whereas most studies investigating adolescents with FASD have been conducted in the United States and Europe (McLachlan et al., 2020). In all cases, the awareness of strengths teachers can build upon, and increased understanding of the individual from their perspective, means improved outcomes for this population are possible.

To fill this gap information about the experiences of adolescents with FASD was collected in the present study, including a balanced perspective between the strengths and struggles across settings. This knowledge could lead to a higher standard of education for adolescents with FASD. Although teachers are only one part of an intricate network of people

responsible for educating individuals with FASD, exploring what adolescents with FASD want teachers to know about their strengths and struggles across settings is an important step toward educating teachers about FASD and ensuring adolescent perspectives are added to the literature. By disseminating themes derived from data in the present study, teachers may develop a deeper understanding of strengths and struggles adolescents with FASD face, learn how to support them in the classroom, and apply their new knowledge to their professional practice.

With the above points in mind, this qualitative descriptive study had two purposes, two goals, and one research question. Operational definitions are also provided because consistent use of language can ensure shared understandings of this research.

Purposes

1. To preliminarily explore adolescents' lived experiences of FASD to discover what they want teachers to know about their strengths and struggles across multiple settings.
2. To consider what can be learned from adolescents' lived experiences and how this knowledge can be used to increase teachers' understanding of FASD and the teaching practices they choose to employ in their classrooms.

Goals

1. To gather first-hand accounts of what life is like for adolescents with FASD and how this affects their educational experiences.
2. To unearth what adolescents with FASD want teachers to know about the strengths they have and the struggles they experience.

Question

1. What do adolescents with FASD want teachers to know about their strengths and struggles in their home, school, and community settings?

Operational Definitions

Strengths and Struggles. *Strengths:* When a day goes well for an adolescent with FASD at school, at home, or in a community setting (e.g., a place such as a church, an activity they excel at such as playing soccer, or a group they belong to such as a video-game club).

Struggles: When a day does not go well for an adolescent with FASD in these settings.

Settings. *Home:* A place of residence such as a house or apartment. *School:* No specific definition, but participants were asked to consider school as a place. *Community:* A group of people to spend time with outside of school (e.g., a sports team, arts-and-crafts group, or video-game group), a place (e.g., a church or a pet store), or an activity outside of a school setting (e.g., shopping).

Research Context. *Primary Researcher:* The individual, Vanessa Boila, who conceptualized and conducted the present research study as outlined in this thesis.

Chapter 2: Ethical Considerations

Positionality and Reflexivity

In qualitative research, researchers often examine positionality as they seek to answer their research question(s). To examine positionality is to self-reflect on three domains: locating the researcher in the research (1) topic, (2) participants, and (3) process (Holmes, 2020). Exploring positionality also requires reflexivity. Cohen et al. (2018) says being reflexive means explaining oneself in the context of their research and trying to understand their potential influences. To this end, reflexivity allows researchers to examine the subjectivity they impose on their research (Birks et al., 2008). Holmes (2020) states if reflexivity is not present, research may be viewed as unethical, which is problematic. In my statement below, I examine all three aspects of positionality whilst being reflexive, and therefore ethical.

Locating the Researcher

Topic

I am a 35-year-old middle-class white woman born and raised in Canada. Despite being in my mid 30s, I do not feel my age, nor do I think I look as old as I am. I believe sexuality is a private matter shared only on a need-to-know basis, so I believe it is okay for others to share only what they feel comfortable sharing. For as long as I can remember I identified as Canadian, but I also identify as Ukrainian. In the past, I wanted to travel to Ukraine to understand my cultural roots, but I am unsure if I will ever go given Russia-Ukraine conflicts. Upon reflecting on learning opportunities that I might miss due to not going, I do not believe first-hand experience is needed to learn about something, somewhere, or someone. I believe I can learn by listening to what others have to say.

Growing up, I lived in a stimulating home environment, and I was privileged. I had access to toys, I was enrolled in extracurricular activities, I was afforded educational support at school, and I had opportunities to learn about religion. I lived with my older sister and both biological parents, and at any point in time a few cats lived with us, so I have always viewed pets as family.

As a young child I had an avid interest in Beanie Baby collecting, and I had opportunities to try soccer, swimming, gymnastics, baseball, martial arts, and sewing classes. Growing up with a father who worked as a Systems Analyst, I had access to the latest computer technology, so I had a keen interest in learning coding skills and making websites. In the early years, I struggled academically and behaviourally, but my school provided individualized support, so I did not fall too far behind my peers. Early on in life my parents had conflicting views about religion, so they baptized me Protestant and sent me to Catholic school. This allowed me to learn more about faith and explore my beliefs. Later in life I became Catholic, so I believe decisions earlier in life are guided by parents or caregivers, but later in life each person serves as their own guide, and they are free to make their own decisions.

Despite having many jobs and roles in my lifetime, I identify most with the roles of teacher and future psychologist. In high school, I spoke with my biology teacher outside of scheduled classes about all sorts of topics. The excitement of being able to build rapport with students, just as she had done with me, sparked my desire to become a teacher. Having been mistakenly signed up for drama class as a teenager, an engaging, creative outlet for building connections with peers was also revealed to me. I believe building rapport and connections is more important than covering the curriculum, so I view efforts to revise the curriculum as wasteful. Until the way the education system is structured changes, I believe little in the field of education will change. Having felt helpless to change inequities I saw, but still desiring to work in a helping profession, I left teaching to study psychology. In my studies, although I never set out to research FASD, as I conceptualized the present study, I saw a place for bridging my teaching background with Dr. Pei's expertise in FASD to *try* to impart change in the world.

Participants

Some people might call me an outsider. I have cousins with learning disabilities and other disorders such as schizophrenia and epilepsy, but I do not know anyone with FASD, and I do not have FASD myself. Someone might assume that because I have an education degree, I

might have prior knowledge about FASD, but this is far from the truth. No matter the reasons for lack of knowledge, however, my view is it is better to admit not knowing and seek to understand from those who are experts. To me, being an expert does not necessarily mean someone has a wealth of knowledge. Instead, being an expert can mean someone who has lived experience.

Possibly due, in part, to being an outsider, I have misperceptions about FASD. During a recent practicum, I assumed all adolescents with FASD struggle academically or have low cognitive ability. After completing a psychoeducational assessment for an adolescent with suspected FASD, and because I had not yet reviewed research on FASD at the time of my practicum, I was surprised to learn FASD may present socially or behaviourally rather than cognitively or academically. After this experience, I realized there is a lot I do not know about FASD, and I have a lot more to learn about people living with the disorder.

Process

My theoretical orientation is primarily humanistic, so this helped me contextualize the research choices I made in the present study. For example, I believe everyone is an expert in their own lives, so to ask a parent, caregiver, or teacher about adolescents' experiences would mean to ignore the expert themselves. I believe adolescents are the experts of their lives and experiences if they are the focus of a study, so they know themselves better than anyone. In addition to this, interview questions I posed focused not only on struggles but also on strengths. This is because I believe it is important to consider everyone's positive attributes rather than solely drawing attention to the negative ones. Humanism, then, is at the core of my beliefs.

Just as my theoretical orientation is part of who I am and the choices I make, I cannot cease to know my teacher lens. This lens undoubtedly guided my process in the present study. As a teacher, I often felt I was tasked with an impossible task. In any given school year, I taught students with so many cognitive abilities, language levels, and other needs I felt it was impossible to meet all their needs. However, I spent a lot of time with them. This time together meant I sometimes assumed I knew what was best for my students even though I may have

been wrong. In the present study, as I listened to responses to interview questions, I caught myself wondering, “Have you tried ___? Did your teacher think to ___?” Sometimes I voiced these opinions aloud, and I may have ignored my beliefs about adolescents being the expert. Ultimately, I knew I wanted to listen without allowing the influence of my teaching background to shape the present study, but this was an impossible task. I could not take the teacher out of the researcher. The two must exist together in the research process.

Tri-Council Policy Statement

Just as there are three domains of positionality, the Government of Canada's (2018) *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2* outlines three core principles: Respect for Persons, Concern for Welfare, and Justice. Using these as a guide, the present study met the following ethical considerations.

Respect for Persons

Obtaining Consent. Prospective participants' parents/guardians were provided informed consent. A Consent Form (see Appendix A) was provided to parents/guardians via email, and the primary researcher offered parents/guardians the opportunity to review the form on the virtual Google Meet platform. This was done because prospective participants were under 18. After parents/guardians reviewed the form consent was obtained. Parents/guardians could provide consent in writing or via a virtual meeting on the Google Meet platform.

Obtaining Assent. Prospective participants provided assent. Following parent/guardian consent, an Assent Form (see Appendix B) was emailed to prospective participants, and the primary researcher reviewed this form with them via email and again on Google Meet before an interview. Verbal assent was obtained after the primary researcher reviewed the form with the participant on the virtual Google Meet platform.

Withdrawing Assent and Data. Prior to an interview, participants were informed they could withdraw at any time. Participants could withdraw from the study by saying they no longer wanted to continue or by exiting the Google Meet platform, without warning, prior to the

completion of all interview questions. Alternatively, participants could indicate a decision to withdraw within two weeks after the interview by sending an email to the primary researcher or to Dr. Pei informing them of their decision. After a two-week timeline had elapsed following the interview, participant data was anonymized indefinitely.

Concern for Welfare

Minimizing Discomfort. Although the present study had minimal risk, a few strategies were used to minimize discomfort related to the use of computers (i.e., screen time) or content discussed. Participants were given opportunities to take short breaks during an interview and were reminded of this throughout the interview. To minimize discomfort participants may have felt about discussing their perceived weaknesses, they were encouraged to share only what they were comfortable sharing and were told they could stop sharing any time. This information was verbally reviewed with participants during the interview and in writing during the assent process.

Protecting Confidentiality. G Suite, including the virtual Google Meet platform, is the approved campus resource used in the present study. Recordings on this platform are encrypted by Google's default security settings. When a Google Meet is scheduled, a participant code was entered for the title of the meeting, and there was no identifying information in the meeting title, description, or link. Prior to an interview, meeting links were emailed to each participant.

Data collected in the present study remained securely stored. Data was stored on the primary researcher's Google Drive; as well, data files remained password protected and were stored on the primary researcher's computer, which was also password protected and encrypted. On the virtual Google Meet platform, interview recordings were uploaded to a folder on the primary researcher's Google Drive. Dr. Pei was the only other person with access to files.

Absolute confidentiality could not be promised. For example, if abuse, neglect, or harm were reported to the primary researcher during the study, she had to report to the appropriate authorities. Limits to confidentiality were clearly outlined in the Consent and Assent Forms.

Providing Resources. Outside of the interview setting, parents/guardians and participants were provided a link to a list of Canada-wide wellness resources in the Consent Form. Parents/guardians were encouraged to reach out to a local resource in the event they required support for themselves or for their adolescent who participated in the study.

Justice

Considering Dual Roles and Power. Dr. Pei runs a private practice and holds various provincial and national positions (e.g., Senior Research and Intervention Lead at CanFASD). Given her networks, Dr. Pei was well-placed to recruit participants. However, some parents/guardians or prospective participants may have had a prior relationship with Dr. Pei, so an imbalance of power could exist. Thus, before recruitment began, it was decided prospective participants and their parents/guardians would be informed their decision to participate or not participate would not affect any pre-existing relationships. Furthermore, Dr. Pei was blinded to who chose to participate and all identifying information was removed before she saw interview transcripts. Thus, during the study, participants were informed of this blinding and told identifying information would be removed from their interview transcript.

Offering Options for Future Research Participation. Options were considered in case prospective participants did not meet the inclusion criteria. An email template was pre-prepared, so if inclusion criteria were not met, an email could be sent to parents/guardians to inform them about other opportunities to participate in research studies. A link to the Alberta Clinical and Community-Based Evaluation Research Team's website was listed in the template, so parents/guardians could find opportunities on the website as they became available.

Chapter 3: Research Approach

Theoretical Framework

Often referred to as Ecological Systems Theory today, Urie Bronfenbrenner's (1977) "ecology of human development" (p. 514) informed the present study. This theory has previously been used to study children and their relationships with other people in various environments. More specifically, this theory indicates children are influenced by five interrelated systems (i.e., the microsystem, mesosystem, exosystem, macrosystem, and chronosystem) with each system influencing the next closest system in the model (Guy-Evans, 2020) and what happens with others in one setting affects what happens in other settings (Bronfenbrenner, 1977). As applied to the present study, Ecological Systems Theory holds that what takes place at school and in the classroom affects interactions adolescents with FASD have with others at home and in their communities, so it is important to explore several aspects of the ecological systems to which individuals belong. This theory also holds that interactions in one environment can affect interactions in another, so people and places are interconnected.

Philosophical Worldview

Philosophical foundations of pragmatism date back to discussions in the 1870s amongst several founding fathers across disciplines such as philosophy, psychology, mathematics, and law (Kaushik et al., 2019). According to Creswell and Creswell (2018), researchers need to identify their philosophical worldview because of its potential to influence their research. The primary researcher's worldview is pragmatic. Pragmatism allows researchers to choose the most suitable methods for answering questions they have about the world (Allemang et al., 2022).

Pragmatist researchers do not ascribe to one exclusive means of knowledge inquiry (Doyle et al., 2020). Instead, they bridge social justice with applied problem solving thereby lending strong justification for exploring individuals' experiences in an action-focused manner to initiate change (Allemang et al., 2022). This bridging is apparent across training models such as in the Scientist-Practitioner-Advocate Model explained in literature about training students in

graduate-level professional psychology programs (e.g., Mallinckrodt et al., 2014). Science can influence practice, and practice can affect the generation of new research or ideas, but social and cultural contexts matter too because they guide decisions about advocating with others or serving as a representative on behalf of others at individual, community, or public levels (Mallinckrodt et al., 2014). Considering the primary researcher's pragmatic worldview paired well with a social-justice lens to examine lived experiences to initiate change within the field of education, the research question was answered using a qualitative approach and qualitative descriptive design.

Research Approach and Design

Qualitative Approach

Aspers and Corte (2019) recently said, "Qualitative research, we argue, requires meaning and this meaning is derived from the context, and above all the data being analyzed" (p. 156). The present study used a qualitative approach because it can help researchers develop a deep understanding of a phenomenon, or of people, places, or groups. In the present study, a qualitative research approach was the most appropriate choice because one of the research goals was to unearth lived experiences of adolescents with FASD.

Qualitative Descriptive Design

A qualitative descriptive design, which is a specific research design, can be used in a qualitative approach. These designs, commonly used in clinical research spanning health care and nursing fields, are useful for examining under-investigated topics (Doyle et al., 2020), understanding participants' subjective experiences (Bradshaw et al., 2017), and improving clinical practice rather than advancing theory or expanding conceptual knowledge (Chafe, 2017). They also allow researchers to gain deeper insight into the topic being investigated (Simon et al. 2015), and they are useful for exploratory research (Doyle et al., 2016, as cited in Doyle et al., 2020) and re-counting participant experience without diving too deeply into theoretical underpinnings (Doyle et al., 2020). Willis et al. (2016) suggests researchers who use qualitative

descriptive designs can create thematic summaries to report the shared themes derived from participants. Clearly, the present study focused on the practicality of the research and results without delving too deeply in theory, so a qualitative descriptive design was the best fit for the purposes and goals of the present study.

Research Methods

Recruitment

Four approaches were used to recruit participants for the present study. First, prospective participants were identified from parent/guardian responses to a Recruitment Flyer (see Appendix C). The primary researcher provided flyers to FASD community networks (e.g., the Alberta Provincial FASD Network, and CanFASD), and they shared the flyers online if they had social media (e.g., a Facebook, Twitter, and Instagram page) or distributed them internally to their members. Individuals at the community networks ranged from a Program Manager for a child and family community service to a Network Coordinator for a FASD network to an Executive Director for a FASD network. These individuals were contacted approximately four times, May 2021, June 2021, July 2021, and October 2021, to share the flyer with their members. All four times every individual replied to the primary researcher to indicate the flyer and recruitment information had been shared amongst their networks. Second, flyers were shared on listservs for the University of Alberta's Department of Educational Psychology and Faculty of Education. Third, Dr. Pei informed clients from her practice about the study. Fourth, the primary researcher recorded a 17-minute video interview with an international FASD educator outlining the study goals and inclusion criteria. This video was shared in early 2022 on his FASD Community Success Facebook page.

Participants

Participants in the study were two Canadian adolescents, ages 13 and 15, with FASD. Although the World Health Organization (WHO, 2022) defines adolescence as a period spanning ages 10–19, the age range for participants in the present study was 13–17. The

reasons for this choice were twofold. First, according to Edmonds and Crichton (2008), adolescents and young adults with FASD between ages 16–20 in their study struggled with reading and comprehension compared to their same-age peers without a FASD diagnosis. Keeping this in mind, the lower end of the age range in the present study was increased (i.e., from age 10 to 13) to ensure comprehension level would not affect participants' ability to respond to interview questions. Second, the researcher was most interested in speaking with adolescents in K–12 schooling. Due to this, the upper end of the age range was lowered (i.e., age 19 down to 17) to try to capture perspectives of adolescents enrolled in K–12. Study criteria allowed participants to be as old as 17. Initially, study criteria allowed participants to be as young as 14 on the low end of the age range, but this was later lowered to age 13 with approval of the Research Ethics Board due to difficulty in recruiting participants from this population and expression of interest from a parent/guardian with a 13-year-old who met the study criteria.

Inclusion and Exclusion Criteria

Participants were included if they met the following criteria: (1) have a FASD diagnosis; (2) are between ages 13–17; (3) have access to a home computer; (4) can use the virtual Google Meet platform independently; (5) can express thoughts verbally in English; (6) can read fluently in English; and (7) can sit for an hour-long interview with or without breaks.

To ensure a representative population of adolescents with FASD, participants needed a FASD diagnosis and had to meet specified age criteria. To participate in a virtual interview without the influence of others, participants required a home computer and the virtual Google Meet platform they could use independently. To provide assent and participate in interviews, participants also had to be able to read and respond in English as no external translation or support services were provided by the primary researcher. Finally, participants had to sit for extended periods of time because it was not feasible to schedule multiple interviews due to constraints on the primary researcher's time. Only the primary researcher conducted participant interviews. There were no additional exclusion criteria.

Sampling

As described by Lavrakas (2008), a purposive sample consists of participants who have a certain degree of expertise and who represent a specific population. In line with this, the primary researcher used purposive sampling in the present study. Undesirably, purposive sampling can limit the population from which the sample of participants is drawn (Doyle et al., 2020), however, participants from a purposive sample can share knowledge and experience related to the research goals and topic under investigation (Ritchie & Lewis, 2003). Participants in the present study represented the Canadian adolescent population, and they had first-hand lived experience of FASD.

Data Collection

Background Information Form

The Background Information Form (see Appendix D), a pre-screening questionnaire created by the primary researcher and set up in Google Forms, was intended for collecting general information about prospective participants, including information about the history of their FASD diagnosis. The form was designed to help determine if prospective participants were eligible to participate. Not all parents/caregivers completed the form and instead relied on email communication to provide information they were comfortable sharing about their adolescent.

Semi-Structured Interviews

Semi-structured interviews are exceptionally useful. Back-and-forth exchanges between researchers and participants occur during semi-structured interviews (Galletta, 2013). By using semi-structured interviews in this way (i.e., a back-and-forth exchange), researchers can learn more about participants' unique understandings of the world and the values they assign to them (Adams, 2016). Interviews can help researchers better understand the perspectives and experiences of others (Pope, 2017). Jamshed (2014) says semi-structured interviews involve obtaining and documenting participant responses to pre-determined yet flexible questions. In

alignment with a qualitative research approach and a qualitative descriptive design, semi-structured interviews were used to collect data.

McGrath et al. (2019) indicate researchers construct data alongside participants. Encouragingly, semi-structured interviews allow researchers to alter planned question sequences as the interview unfolds (McIntosh & Morse, 2015). Given the malleable aspect of semi-structured interviews, McGrath et al. (2019) explain if participants do not interpret questions as the questions were intended to be interpreted, questions can be refined after initial interviews. Semi-structured interviews are also useful because of their flexibility; they are neither too rigid nor loose. In relation to the present study, semi-structured interviews were useful because they allowed for a flexible yet authentic discussion between each participant and the primary researcher. A semi-structured interview allowed the primary researcher to direct the interview and rephrase questions as needed.

To try get a Canada-wide view, one-on-one semi-structured interviews with the primary researcher and a participant were conducted on the virtual Google Meet platform, thereby not limiting participants to a certain geographical region. Based on Mikuska's (2018) suggestions, participants should receive interview questions before the interview to help reduce anxiety they may feel. In accordance with her suggestions, participants received an Interview Questions Preview (see Appendix E) in their inbox at least 24 hours prior to their scheduled interview. This preview was emailed directly from the primary researcher to each participant. As there was no need for visual recordings but no option in Google Meet to record audio only, participants were asked to turn their cameras off during the interview. Although the interviews were expected to take up to an hour, on average they lasted approximately 30-minutes per participant. Following each interview, the primary researcher completed a transcription. An Interview Timeline (see Appendix F) and Interview Script (see Appendix G) were developed to guide the data-collection process and to ensure each interview was conducted with a high degree of consistency.

By using semi-structured interviews in the present study, adolescents shared their unique interpretations of the world. They had the opportunity to share the personal values ascribed to their own lived experiences. Only the primary researcher conducted the interviews. Semi-structured interviews allowed the primary researcher to learn about the lived experiences of adolescents with FASD while simultaneously providing space for an authentic conversation between the primary researcher and participants to unfold. Once all interviews concluded and data were analyzed, participants had the opportunity to participate in a follow-up interview to check data were an accurate representation of adolescents with FASD.

Interview Questions

Feedback from others is an integral part of question development. Agee (2009) suggests research question development should be an ongoing process whereby questions are frequently revised and refined; that is, the research journey is mapped, but there is flexibility to account for the unexpected. The same holds for developing interview questions. Obtaining multiple perspectives about the “right” question to ask and appropriate words to use was done to help guide the development of interview questions. To this end, feedback was sought from caregivers in the Family Advisory Council (FAC) at CanFASD. These individuals were consulted about the suitability of question content. A member of the FAC said:

Success and setbacks are pretty broad. Some individuals might need a bit more prodding questions like “When does school go well? Can you tell me what helps school go well for you? When do you have trouble at school? What makes school hard for you?” Success is an abstract concept which might be difficult for some to understand what you want from them (personal communication, February 16, 2021).

The initial interview questions were revised after receiving this feedback.

Eight questions were asked altogether. Two interview questions pertained to demographics (i.e., current age and home province). The remaining six questions corresponded to strengths (three questions) and struggles (three questions) participants experienced at home,

in school, and within community settings. With Mikuska's (2018) suggestions in mind, questions placed earlier in the interview were designed to be easier, and questions later in the interview were designed to be more difficult. Presenting questions from easy to difficult was done so participants might feel more comfortable with the primary researcher and the interview process. For question content, multiple settings were considered because Skorka et al. (2020) suggest what takes place at home and in the community affects educational environments and vice versa. Although some questions focused on strengths, other questions focused on struggles. This balanced approach was taken because knowledge of strengths and struggles could inform best practices in teaching and contribute to positive outcomes for adolescents with FASD.

Processes

A Procedural Overview (see Appendix H) provides a list of the steps taken by the primary researcher and participants during the study. Along with this overview, a Sample Initial Email – Parents/Guardians (see Appendix I), a Sample Initial Email – Participant (see Appendix J), a Sample Follow-up Email – Parents/Guardians for participants who were eligible to participate (see Appendix K), a Sample Follow-up Email – Parents Guardians for participants who were ineligible to participate (see Appendix L), and a second Sample Follow-up Email – Participant (see Appendix M) were available for efficient communication, and to provide direction to parents/guardians and participants during the study.

Data Analysis

Thematic Analysis

Thematic analysis is useful because of its flexibility and capacity to yield results easily understood by a wide audience (Braun & Clarke, 2006). Clarke and Braun (2014) say thematic analysis is useful because it allows researchers to recognize and analyze patterns or themes in qualitative data. In the present study, thematic analysis was used to discern themes across two participants. Oftentimes, researchers will use qualitative data-analysis software such as Nvivo to identify codes and themes. QSR International (2022) says Nvivo can help researchers locate

themes to formulate conclusions. Due to the small sample size in the present study, the primary researcher did not require software. Guest et al. (2012) suggests qualitative data-analysis software is optional if a study team consists of fewer than two people, there are less than 20 files in a dataset, the goal of the analysis is exploratory, and the study is simple and not too complex. All these guidelines were met in the present study, so the primary researcher did not use any software packages and completed thematic analysis by hand.

To conduct thematic analysis, Clarke and Braun (2014) say researchers use a top-down approach (i.e., using theory to guide the analysis) or a bottom-up approach (i.e., using data to guide them while concurrently recognizing their pre-existing knowledge and assumptions will influence the process). The present study was exploratory, and aside from situating the study within a theoretical framework, theory was not used to guide the analysis, so the primary researcher used a bottom-up approach. Data collection and analysis in the present study therefore followed Braun and Clarke's (2006) recursive phases requiring six steps.

The steps were as follows. First, the primary researcher *familiarized herself with data* by listening to audio recordings more than once after the initial interviews, transcribing interviews by hand using a word processing software, Microsoft Word, and memoing. Re-listening, hand transcribing, and memoing all served as ways to familiarize herself with data. Second, she *generated codes* relevant to the research question. Third, she *scanned codes for themes*. Fourth, she *reviewed themes* individually and with Dr. Pei. Fifth, she *assigned names to themes*. Sixth, she *contextualized the results* in a cohesive manner (see Chapter 4). The process was very iterative, with multiple revisions, until there was shared agreement with Dr. Pei.

Saturation

Moser and Korstjens (2018) suggest some qualitative studies require fewer than 10 interviews, but data saturation (i.e., when no new themes emerge and previously identified themes are continually found) is important to consider when deciding whether to continue collecting interview data. In some instances, researchers require far less than 10 participants to

reach saturation whereas other researchers need more. DeJonckheere and Vaughn (2019) say enough interview material is gathered when no new information is added by conducting more interviews. The topic and inclusion criteria were focused and narrow in the present study, so it is possible two interviews were sufficient for saturation. Without additional interviews, however, it was not possible to be certain saturation was reached, yet it was not practical to interview more than two participants from the population under investigation because only two participants volunteered to be interviewed.

Although saturation may not have been reached, the pre-planned analysis as identified in a data-analysis plan during planning stages of the research and in the ethics-board approved documents was thematic analysis. Changing the analysis plan *after* data collection would not only err on the side of unethical practices, but doing so had potential to add researcher bias beyond the bias already present in a qualitative approach. Accordingly, the original data-analysis plan, conducting thematic analysis to analyze data, did not change.

Memoing

Memoing can be used to enhance almost any qualitative approach (Birks et al., 2008). Memoing is a flexible process whereby a researcher freely reflects on their data without being bound to rules such as grammar, considers what they have learned from data, and records their thoughts in a place such as a notebook (Memos and memoing, 2008). Qualitative researchers require self-awareness (Mauthner & Doucet, 2003), and engaging in memoing is one way to be a reflective, self-aware researcher.

The primary researcher engaged in memoing immediately following each interview. This allowed her to self-reflect on overt statements and covert observations, and how her positionality influenced the interview. In one memo following the second participant interview, the primary researcher made the following note: "I noticed some themes re-occurring already." This memo is evidence to suggest only a few interviews may have been required to reach data saturation.

Data Validation

Researchers strive to use knowledge acquired in their research pursuits and apply it to practice, so it is imperative that several individuals, from practitioners to researchers to the public, view research as genuine and trustworthy (Nowell et al., 2017). As defined by Lincoln and Guba (1985), trustworthiness has four components: credibility, transferability, dependability, and confirmability. Each component, as it applies to the present study, is discussed next.

Credibility

Credibility requires comparing the “fit” between participants and the researcher’s portrayal of them (Schwandt, 2001, as cited in Tobin & Begley, 2004). Carlson (2010) holds similar views because they say member checking can be used to verify data can be trusted. In a talk with M. Quintanilha (personal communication, March 2, 2021), she suggested using member checking to determine if information shared by participants with the researcher has been captured as best and as accurately as possible. Carlson (2010) further explains during the member-checking process, participants can be given interview transcripts and asked to confirm or disconfirm the accuracy of the findings (Carlson, 2010). As applied to the present study, rather than sending a full transcript for participants to review, in part because their abilities such as reading ability were unknown, they were emailed the same instructions (see Appendix N), including a 1-page overview of themes (see Appendix O). They were offered the opportunity to respond with feedback via email and/or participate in a follow-up interview to discuss any inaccuracies with the identified themes. After providing participants with the 1-page summary and a 1-week window to respond with feedback or schedule a follow-up interview, none of the participants provided a response or any feedback. Although no feedback was received, some themes and sub themes changed slightly in the final revisions of this document, but the changes were so minor they did not warrant another follow-up with participants.

Transferability

Transferability refers to the extent to which the research generalizes to other places (Nowell et al., 2017). For these places to gauge transferability as it applies to their individual practice site, Lincoln and Guba (1985) suggest researchers use thick description. In qualitative research, thick description includes formulating accurate descriptions and interpretations of behaviour, so it is understood by anyone far removed from the research; contrarily, thin description only accounts for covert, surface-level meanings (American Psychological Association [APA], 2022). As applied to the present study, the primary researcher's job was not to state how this research may generalize across multiple domains or settings, but their job was to provide descriptions and interpretations of participants' experiences to allow others to decide how results of the present study might apply to them and to the settings they practice in.

Dependability

Dependability refers to thoroughly documenting the research process (Tobin & Begley, 2004). It includes ensuring research can be consistently replicated, so anyone following the same protocol would likely derive similar conclusions free from contradictions with the initial findings (Koch, 1994). One way to do this is by keeping a log (e.g., note taking or journaling) explaining decisions made during the research process. As applied to the present study, the primary researcher documented the research process (e.g., in the appendices she provided email templates, included the exact script for semi-structured interviews, and inserted a 1-page overview with the sequence of steps she followed). In addition, she engaged in memoing and kept a record of thoughts, observations, feelings, and reactions.

Confirmability

Confirmability, the last component, refers to asserting results and conclusions that are informed from data (Tobin & Begley, 2004). To do this properly, Koch (1994) recommends finding ways to help others understand the rationale for their research decisions, which can be done when researchers clarify their guiding theoretical frameworks, methodological decisions,

and choice of data-analysis procedures. As applied to the present study, in this chapter, the primary researcher included descriptions of the theoretical framework and her worldview as well as descriptions for her choice of methodology and data-analysis procedures.

Chapter 4: Results

Three broad themes were generated from the interviews: Adolescents with FASD want their teachers to know they (1) are aware of some ways to manage their emotions and some of what adds to their struggles, (2) have preferences for the ways they learn, and (3) value and desire meaningful relationships. In the first broad theme, participants identified they want their teachers to know they are aware of their emotions and struggles. Three specific sub themes were identified within this broad theme. Specifically, participants want their teachers to know what helps them relax, what they are good at, and they know some things are hard for them.

In the second broad theme, participants identified they want their teachers to know they have preferences for the ways they learn. Two specific sub themes were identified within this broad theme. Specifically, participants want their teachers to know they enjoy learning when it is fun and interactive, and they want to show you.

In the third broad theme, participants identified they want their teachers to know they value and desire meaningful relationships with others. Three specific sub themes were identified within this broad theme. Specifically, participants want their teachers to know they have a hard time with some social interactions, they want to connect with others, and they interact with others in their own way.

Theme 1: I am aware of some ways to manage emotions and some of what adds to my struggles

Participants shared examples of experiences they have had, including ways in which they have been able to help themselves feel better. They revealed awareness of their needs and challenges in both school and home, but also recognize strategies they use. Participants spoke about what makes them feel at ease and comforted. They also spoke about special skills and talents, and indicated they are aware of the challenges they face and how certain environments affect them in positive or negative ways.

1a. I know what helps me relax

The participants expressed awareness of what helps them relax. They shared they like spending time with animals, such as snuggling with a cat or dog, or riding horses. One participant thought they might enjoy a classroom pet. They also engaged with their own pets during the interview, such as having their cats or dogs nearby the interview room. Participants agreed having comfort items (e.g., blankets, stuffed animals, or something else soft like a bed) might also help them to feel better in the classroom. Furthermore, one participant explained they do the following to take their thoughts away from unpleasant things when a day is not going well: "Listen to music; watch movies; focus on schoolwork; go to the mall."

1b. I know what I am good at

Participants named what they believe they are good at. They excel at some physical activities. One participant remarked they are a fast runner, just like their horse, and they are such a fast runner, "I can even beat my dog in a race." The other participant said, "[The day] goes well when I play video games," and they continued to explain they engage in a variety of activities through the popular video game, Roblox.

1c. I know some things are hard for me, but I can cope

Participants described challenges they have. Generally, these challenges were linked to cognitive skills. For instance, they see themselves as easily distracted: "I get so distracted, so someone will ask me a question and I'll be like...wait, what did you say?" During the interview, one participant shouted for a family member to remove the dog from the room, so sometimes pets were distracting for participants. Memory, or learning ability, was also identified as weak: "I'm very bad at remembering." Sometimes participants also required support such as asking for a re-statement of questions or a definition for words they were trying to express. This was the case when a participant asked for clarification about a word they wanted to use: "What does 'neglected' mean again?" Despite these challenges, participants have developed strategies, such as using colourful markers or highlighters to write words to help with remembering.

Participants believe some of their challenges interfere with life skills. They find tasks such as preparing meals difficult. Participants have trouble adhering to rules if they do not make sense to them. As an example, some teachers do not allow bathroom breaks when participants need and ask for them. One participant said, "Let's say I needed to go to the washroom. She wouldn't let me."

In addition to the cognitive challenges participants spoke about, participants said adapting to certain environments is difficult for them. They explained how being allergic to things like grass affects their enjoyment of activities. They also mentioned how being surrounded by noise, such as being near loud siblings, is not enjoyable for them either.

Theme 2: I have preferences for the ways I learn

Participants suggested they prefer to learn in certain ways. They want their teachers to know learning can be enjoyable for them when activities are fun, engaging, and interactive. It suggests participants want their teachers to know they appreciate having opportunities to share and show, not just tell someone about something.

2a. I enjoy learning when it is fun and interactive

Participants reported various learning activities are enjoyable for them. They enjoy reading comics and graphic novels, and they like playing games with learning components. Participants had interests spanning several games. They readily listed games such as Tower Defence, Crazy Kingdom, Tower of Doom on Blooket, Egg Incorporated, Makeover Studio 3D, Wordscapes, the game-based learning software Kahoot, the video-streaming platform YouTube, and Messenger Kids, suggesting they are familiar with these games, play them often, and may experience success when they use them. Some games they spoke about were distracting yet fun games, some games they shared incorporate specific learning activities, and other games were video platforms allowing for teaching or sharing of content in applied and visually appealing ways. Evidently, participants get enjoyment from a variety of games, and they find learning pleasurable when teachers incorporate games in their lessons. A participant's statement

captures these ideas succinctly: “I enjoy that I get to learn and also, um, [I get to] have fun and [play] games.”

2b. I want to show you

Throughout the interviews, participants expressed a desire to interact visually even though initial interview instructions encouraged participants to leave their camera off. At times participants expressed a desire to show and tell. For instance, one said, “Let me just...show you.” Visual expression often accompanied efforts to explain points they appeared to struggle to explain through language alone. One participant shared their screen with the primary researcher to explain games and activities they enjoy playing. Another participant proceeded to show the primary researcher an object such as a squishy toy they received from their psychiatrist.

Theme 3: I value and desire meaningful relationships

Participants suggested they prioritize relationships. They want their teachers to know although they experience difficulties with some social interactions, they want to connect with others. It suggests participants have their unique way of interacting with others.

3a. I have a hard time with some social interactions

Participants shared that some social interactions can be difficult for them. They reported these difficulties impact them in more than one way, as they experience negative peer interactions, such as bullying, as well as few social interactions. When asked what might make school better, one participant said, “Bullying people not being there.” Although they were able to identify this as a concern, and a barrier to enjoying school, participants had more difficulty identifying solutions to this challenge. For instance, they reported they do not want to tell teachers bullying is bothering them, “I never really just say it to a teacher because I don’t want to make a big deal of it.” Participants also believe even when teachers know about bullying, their teachers do not do anything to help.

3b. I want to connect with others

Participants expressed a desire to learn about others, though sometimes they used

impulsive or unexpected comments to create connections. As one example, one participant abruptly asked the primary researcher about her personal life such as wanting to know her current age. As another example, participants demonstrated a desire to connect with anybody. Participants made statements such as, "I didn't have a lot of friends at school," yet they concurrently expressed openness toward being friends with bullies if they were nicer to them. Participants also spoke about how the pandemic has limited their ability to connect with others. For example, regarding attending anime conventions with friends, one participant said, "I would do it . . . if the pandemic was over I would [go]," suggesting opportunities to form meaningful connections with others have been limited over the last few years even though adolescents with FASD desire connection.

3c. I interact with others in my own way

During the interviews, participants interacted in ways most comfortable for them. They sometimes used terms or language most familiar to them as they responded to the researcher's questions. For instance, they said things like, "Np as in no problem" and "Jawas," but clarified: "I just wanted to say something random. That's me!" Participants also moved around a lot, so they were most expressive and vocal when they had opportunities to move. Both participants took optional breaks and walked away from the computer screen at least once during the interview.

Chapter 5: Discussion

The purpose of the present study was twofold: (1) to explore the lived experiences of adolescents with FASD and what they believe teachers need to know about their strengths and struggles across settings, and (2) to consider how this information shared by adolescents with FASD can be applied to practice. First, the need to collect this information arose from studies such as Skorka et al. (2022) stating investigating strengths, not only struggles, is important for learning how to support adolescents. Second, the need arose from parents/caregivers, researchers, and individuals with FASD across studies (e.g., Bashista, 2022; Brenna et al., 2017; Pei et al., 2015; Petrenko et al., 2014) who are concerned teachers are not equipped or they are underprepared to meet the needs of individuals with FASD in the classroom. Third, the need arose from studies such as Skorka et al. (2020), stating examining the lived experiences of children and adolescents with FASD from their perspective, and moving beyond data collection using mainly parental or caregiver reports, is needed.

To understand what adolescents with FASD want their teachers to know about strengths and struggles across home, school, and community settings, first-hand accounts were collected from them. Efforts were taken by the primary researcher to ensure strengths and struggles were considered in the research process. As it turns out, adolescents have lots to share about their strengths and struggles across settings, and three broad themes were derived: (1) I am aware of some ways to manage emotions and some of what adds to my struggles, (2) I have preferences for the ways I learn, and (3) I value and desire meaningful relationships.

Review of Themes: Implications for Teachers and Adolescents with FASD

Review of Theme 1

The first broad theme, *I am aware of some ways to manage emotions and some of what adds to my struggles*, revealed adolescents with FASD have some self-awareness. They are keenly aware of challenges they face, yet also have developed ways to manage emotions and cope with their struggles. Some individuals with FASD have intelligence on par with, or above,

their same-age peers (Odishaw & Snart, 2005), so their cognitive functioning may allow them to develop a deep understanding of themselves and others. As evidence, all 22 Canadian children and adolescents in Stade et al.'s (2011) study who participated in in-depth interviews revealed they understood their disability well, including how it impacts their daily living. Keeping this in mind, teachers may consider asking adolescents with FASD about their coping strategies for addressing struggles because, ultimately, adolescents with FASD are self-aware and therefore experts of their lives.

Review of Sub Theme 1a. In sub theme 1a, *I know what helps me relax*, adolescents with FASD revealed they are comforted and relaxed, mostly by the presence of pets or certain objects, and when they distract themselves from their struggles. Literature confirms spaces containing comfort objects, such as cushions or toys, or access to enjoyable activities, have a relaxing effect for school-age children with FASD (Carpenter, 2011). Carpenter (2011) says what works well is a designated place in the classroom they can go when feeling dysregulated or needing to calm themselves. Adolescents with FASD could inform teachers they need to visit the designated place, or teachers could allow access without requiring permission, thereby acknowledging adolescents' self-awareness. It may therefore be important for teachers and adolescents with FASD to have a plan outlining objects they can use, and where to go or what to do, to ensure the adolescents do not appear noncompliant with classroom rules when they may in fact be exercising self-awareness and self-regulation strategies to help them relax.

The curriculum is important to discuss as it relates struggles. Duquette et al. (2007), for instance, state even if adolescents and young adults with FASD can access specialized classes and individualized supports, the curriculum does not always align with their needs. In the present study, one adolescent spoke about activities to help them take their mind away from struggles. Millar et al. (2017) says special equipment such as headphones can support children and adolescents with FASD in the classroom by reducing distractions around them. Despite the potential benefits of equipment or activities (e.g., listening to music, watching a movie, or visiting

a place), these could be perceived as non-academic or noneducational. Returning to the ideas of Duquette and Stodel (2005), the most successful children, adolescents, and young adults with FASD are those with teachers and caregivers who take an advocacy role in their lives. Ideally, teachers will advocate for the benefits of activities (e.g., listening to music, watching movies, and so on) even if not a central part of the curriculum. Nevertheless, if teachers are not willing or able to assume this responsibility, adolescents with FASD or their parents may need to fill the role—not an easy task without coordinated support from the home and school.

Review of Sub Theme 1b. In sub theme 1b, *I know what I am good at*, adolescents with FASD revealed they are aware of what they excel at. Sanders and Buck (2010) describe skills parents and caregivers of children, adolescents, and young adults with FASD have witnessed such as athleticism, artistic ability, or putting forth high effort. When young adults with FASD are seen not for their struggles but for strengths, they may form a positive view of themselves (Burles et al., 2018), and can participate meaningfully in day-to-day activities (Brenna et al., 2017). Adolescents in the present study listed athletic activities such as running, and playing video games, as some of their strengths. Their ability to excel in these and have others observe their accomplishments may help them recognize pre-existing strengths, view themselves more positively, and witness how persistence in and effort toward a task can further develop skills.

Review of Sub Theme 1c. In sub theme 1c, *I know some things are hard for me, but I can cope*, adolescents with FASD revealed they have difficulty with using cognitive abilities and completing academic tasks, completing life-skill activities, adhering to behavioural expectations, and adapting to certain environments. These findings were consistent with previous literature. For example, cognitive difficulties affect memory and attention in individuals prenatally exposed to alcohol (Kable et al., 2016), and in Timler and Olswang (2001) a parent who was interviewed about their child with FASD described lapses in memory as knowledge one day but not another. Adolescents with FASD may also experience academic difficulties (Duquette et al., 2006), and as noted by Brown et al. (2012), some of them misbehave when unable to self-regulate.

Regardless of their struggles, adolescents with FASD often come equipped with their own coping strategies—another strength of theirs, and teachers can support them in their strategy use. In the present study, adolescents named strategies, such as drawing with colourful markers, or they demonstrated strategies, such as asking for definitions. Adolescents with FASD in Skorka et al. (2022) indicated artistic activities reduced frustration they felt during academic tasks. In line with this, it is possible adolescents in the present study use drawing to reduce their undesired feelings. Expanding further, an adolescent with FASD in Skorka et al. (2022) demonstrated pride in their resourcefulness. Upon further reflection, adolescents in the present study may have been aware of their own resourcefulness or were intuitively resourceful. Adding to this resourcefulness, Kleinfeld and Westcott (1993) provide strategies for teachers to consider: preferential seating at the front of the classroom and in the same desk; using tape to signify physical boundaries; turning off bells; keeping the classroom door shut; and adjusting blinds. Considering these strategies have been around for quite a while, and adolescents with FASD know and use some of their coping strategies given their resourcefulness, teachers may not need to add many new strategies to their repertoire. Ultimately, children and adolescents with FASD can use strategies, such as pointing, mental rehearsal, or chunking, when supported by adults, (Makela et al., 2019), so teachers can co-create strategies with adolescents with FASD by identifying the ways in which strategies may or may not be helpful.

Review of Theme 2

The second broad theme, *I have preferences for the ways I learn*, revealed adolescents with FASD enjoy learning when learning is so fun it does not feel like learning. It also revealed they have a preferred way of learning, which includes demonstrating or explaining what they know or can do. These findings are consistent with current literature. As an example, again in Skorka et al. (2022), an adolescent with FASD expressed they enjoyed school when lessons were fun because of the efforts of their teacher. Along with this, Flannigan et al.'s (2021a) review of the FASD literature on strengths found individuals with FASD are often proud of themselves,

gather strength from aspects of themselves such as their cultural identity, and are generally confident in their abilities despite some struggles they experience. To this end, adolescents with FASD in the present study preferred to learn when learning held their interest, they could share parts of themselves such as their identity, and they boasted about what they were proud of.

Review of Sub Theme 2a. In sub theme 2a, *I enjoy learning when it is fun and interactive*, adolescents with FASD revealed they enjoy learning when teachers engage them in the learning process. Adolescents with FASD in the present study indicated if teachers make learning fun, they enjoy educational activities such as reading, so it seems adolescents with FASD are eager to learn some of the time, but not of all the time. Blackburn et al. (2010) say teachers can adjust instructional techniques for children with FASD by highlighting their unique strengths and incorporating their interests into instructional activities. For the adolescents in the present study, gaming was an enjoyable activity that held their interest. They knew lots about a variety of games and expressed strong interest in them, so this suggests adolescents with FASD would be more inclined to enjoy school if activities they enjoy and excel at are incorporated. It is therefore important for teachers to find out what excites adolescents with FASD and incorporate or plant, if you will, these “seeds of excitement” into classroom instruction where possible.

To personalize learning and cultivate a positive school experience, teachers need to recognize the vast diversity across brain and behaviour development, appreciate how this diversity affects the needs of those with FASD, and integrate this knowledge and understanding into teaching (Millar et al., 2017). To elucidate, Millar et al. (2017) say knowing what children and adolescents with FASD are passionate or enthusiastic about, as well as learning about their strengths and weaknesses, can influence what teachers do in their classrooms to promote positive learning experiences. Blackburn et al. (2012) says families can support this process because they could relay information to the school about how their child is managing with the curriculum. In Brenna et al. (2017), a young adult with FASD indicated how his passion for acting led to his increased motivation to be punctual even though he viewed being on time as one of

his weaknesses. Understanding strengths and weaknesses, therefore, has a large role to play in creating an enjoyable learning experience in the classroom.

Review of Sub Theme 2b. In sub theme 2b, *I want to show you*, adolescents with FASD revealed they are eager to share by showing rather than telling. Given this information, allowing adolescents with FASD to lead, meaning they could assume the role of the “expert” in the classroom, may be a useful strategy for teachers. Pettenger et al. (2014) says incorporating simulation activities into the classroom allows for a learner-focused educational environment. In other words, focus shifts from the teacher to allow the learner to be the guide. Recalling personal strengths, such as some adolescents with FASD speaking more than one language (Kippin et al., 2018), learner-centred classrooms could provide adolescents with FASD more opportunities to show what they know or can do. Learner-centred classrooms could also allow them to learn in ways they prefer, which is another way for them to showcase their strengths.

Review of Theme 3

The third broad theme, *I value and desire meaningful relationships*, revealed relationships are very important to adolescents with FASD, but despite the importance they place on relationships, they experience difficulties with interpersonal communication. They are not always sure how to communicate interpersonal struggles. Sometimes they are unsure if communicating concerns about interpersonal issues, such as bullying, is a good idea or not.

Review of Sub Theme 3a. In sub theme 3a, *I have a hard time with some social interactions*, adolescents with FASD revealed they have few positive social interactions with others. This corresponds with research suggesting adolescents with FASD have trouble establishing social connections with their peers (Duquette et al., 2006). Although they have struggles, adolescents and young adults with FASD are resilient (Rogers et al., 2013). Bearing in mind their resilience, teachers can try to foster it. As an example, individuals with FASD can consider developing connections with a supportive, positive role model (Blackburn et al., 2012). Fittingly, teachers can consider strategically pairing individuals with FASD with adults or same-

age peers. As another example, teachers can respond to the needs of children and adolescents with FASD by using scripts and role play in the classroom (Millar et al., 2017). As described by Carpenter (2011), social stories are useful tools because they provide opportunities to rehearse what to do or say before encountering social situations. Activities like these would provide opportunities to practice social interactions with supportive individuals such as teachers or other role models. All things considered, though social contexts are difficult for adolescents with FASD to navigate, adolescents with FASD are resilient and can therefore engage in ongoing practice with the support of their teachers, other adults, or supportive peers.

Unfortunately, individuals with FASD often experience bullying and its negative effects (Wilhoit et al., 2017), a common thread weaved throughout the interviews with both adolescents in the present study. What is alarming is the adolescents revealed they did not always inform teachers about bullying. In response, a few action steps could be considered. Take, for example, Spriggs et al. (2007) who says schools can have policies to ensure hallways are monitored by school staff and a school-wide set of rules can be created and enforced. Other environments or people can lessen the occurrence of bullying and its negative effects. This is the case in Skorka et al. (2022) who shares advantages of positive relationships, explaining adolescents with FASD sometimes seek support from their peers or caregivers to complete activities, cope with emotions, or participate in social activities. The young adult in Brenna et al. (2017), for example, said he is more likely to consult with a peer than a teacher, and he suggested implementing a support system whereby individuals with FASD could access a non-judgemental support system in and out of school. Duquette et al. (2006) say they do not just need a positive support person; instead, they need an advocate. Although not all relationships are positive or supportive, to reap the benefits of the strongest and most positive ones, individuals with FASD could work with a supportive adult or peer to brainstorm actions they can take if or when they encounter bullying. Pacer Center, Inc. (2020) has a sample plan and a template available.

Review of Sub Theme 3b. In sub theme 3b, *I want to connect with others*, adolescents with FASD revealed they desire meaningful connections with others. Intriguingly, they said they would consider being friends with a bully at some point in the future. This confirms Blackburn et al. (2012): Individuals with FASD are forgiving. Although an individual with FASD was slightly above the adolescent age range in Burles et al.'s (2018) study, their research revealed young adults with FASD have a strong desire to fit in; due to this, sometimes they misbehave to win approval from others. This information might be concerning to anyone who works with the FASD population given high numbers of individuals with FASD suspended or expelled from school (Streissguth et al., 2004). Without a doubt, individuals with FASD, young or old, struggle to regulate behaviour, but this insight about how they try to fit in, even at the expense of getting into trouble, provides another important consideration for teachers. Teachers must seek to understand the reasons underlying behaviour. Millans (2015) says some children and adolescents affected by prenatal alcohol exposure may benefit from a functional behavioural analysis by a trained professional to better understand their behaviour. Seeking to understand motivation for behaviour may be something teachers have heard again and again, but nonetheless it serves as an important reminder.

Review of Sub Theme 3c. In sub theme 3c, *I interact with others in my own way*, adolescents with FASD revealed they have unique ways of relating to others, such as using certain phrases to express themselves. Statements such as, "That's me," suggests they have likely formed, or are at least in the process of forming, a unique sense of identity. At this point in development, their sense of self may provide a safe and comfortable outlet for interacting with others. Some of the adolescents with FASD in Skorka et al.'s (2022) study indicated they express themselves by styling their clothing, decorating their bedrooms, or creating art. As noted earlier, individuals with FASD have captivating personalities (Blackburn et al., 2012), so their unique ways of expressing their identity may be a strength; however, they could also be weaknesses. For instance, their way of interacting with others may suit who they believe they

are. On the other hand, their way of interacting could make it more difficult to relate to others because they might not interact or express themselves in the same way others do.

For adolescents in the present study, when interacting with the primary researcher, physical movement was something they both did. They may have had an additional diagnosis because Popova et al. (2016b) found many individuals with FASD have a comorbid condition such as disordered attention or conduct. However, suggesting they had an additional diagnosis is merely speculative. Equally important to consider, adolescents in the present study may have been more inclined to move during the interviews because of the benefits of exercise. To illustrate, executive functioning is often impaired in children and adolescents with FASD (Kingdon et al., 2016), yet moderate exercise enhances their executive functioning (Varigonda et al., 2020). It is possible adolescents in the present study were using a strategy, exercise, because it assisted them with holding a conversation. After all, physical exercise improves cognitive functioning for a range of individuals, young and old, and has a variety of biological and psychological benefits (Mandolesi et al., 2018), though Varigonda et al. (2020) suggest running is the most efficacious. In short, teachers may want to allow anyone in the classroom, not only adolescents with FASD, to take movement breaks or move as they learn.

Limitations

There were a few limitations in the present study. First, there were only two participants, so questions remain about whether saturation was achieved or not, but Bradshaw et al. (2017) states, "Data saturation is often referred to in a pragmatic manner to signal the end of data collection" (p. 4), so saturation is a likely but not an absolute outcome. One reason for low interest may be due to anxiety about being interviewed, especially in the absence of a caregiver. In Skorka et al. (2022), two of four participants with FASD who were interviewed about their lived experiences felt anxious about being interviewed and were only able to participate when their caregiver was present in the interview and helped relay information. In the present study, to ensure authentic responding, caregivers were not encouraged to be present, so this may have

restricted the number of participants. Another plausible explanation for low interest is the COVID-19 pandemic. The pandemic may have been a barrier in recruitment because of families' limited capacity to engage due to pressures the pandemic put on multiple aspects of life.

Second, given such a specific population, it was not possible to pilot test the interview questions with adolescents with FASD before conducting the actual interviews. McIntosh and Morse (2015) state pre-testing can be helpful for interviewers because it provides a chance to rehearse how an interview may unfold, and it helps interviewers gauge how participants may respond and if questions asked help to derive the intended information or not. It is quite possible different questions, or questions asked in a different way, may have unearthed more or different information about what adolescents want teachers to know about their strengths and struggles. Relatedly, members of the FASD community were invited to provide input on the interview questions, but they were not invited to help formulate the research question. Had they been invited at the conceptualization stages of the study, the research question may have changed, and this too may have unearthed more or different information.

Third, the primary researcher relied on self-report to gather information, so she did not collect detailed data (e.g., health and medical records) pertaining to the adolescents' diagnosis, and having limited experience with conducting qualitative research, she was a novice to memoing. For the former, having more background information about comorbid conditions, for instance, may have helped disentangle reasons for certain behaviours such as excessive movement. As for the latter, memoing is not reserved for a specific research phase (Birks et al., 2008), yet the primary researcher only created memos after the participant interviews. Had she created memos from conceptualization to dissemination, she may have gained new or deeper insights about herself or her research.

Fourth, to ensure accessibility of the data, rather than sharing entire transcripts, a 1-page summary of emergent themes and sub themes were shared with participants. However, none of them responded, so it remains unknown if the themes captured everything they wanted to share.

One interesting suggestion provided by Doyle (2007) is allowing participants to choose how member checking is done. If the primary researcher took this approach, she may have had a higher chance of receiving a response from all participants. Although Doyle (2007) mainly writes about member checking with older women, their insights such as providing paper or audio copies of transcripts to participants or getting someone to read the transcript aloud to them apply to the present study because these approaches have been used for the member-checking process. Carlson (2010) expands on this by suggesting participants could select quotes that are used for the final publication, which could serve to empower participants as they take on a larger, more active role throughout the research process.

Fifth, as the present study employed a qualitative descriptive design, a fundamental goal of this research was to create a bridge between the findings and application. Collecting data does not ensure teachers can access data, nor does it ensure increased knowledge and understanding of FASD amongst teachers, or alterations in how they teach adolescents with FASD in their classrooms. Millans (2015) says teachers would benefit from training on prenatal alcohol exposure including strategies for the classroom and for working collaboratively with caregivers. Boys et al. (2016) says most teachers are open to learning more about FASD. What can the primary researcher do to communicate suggestions from the literature and the results from the present study to teachers? Preliminary ideas include submitting proposals to present at a local teachers' convention, contacting the Alberta Teachers' Association to propose a professional development workshop for its members and collaborating with FASD organizations to prepare these presentations or workshops. A collaborative approach to dissemination may be important because, as documented in Timler and Olswang's (2001) case study, perspectives about strengths and weaknesses across home and school settings are perceived differently between parents and teachers. As a certified teacher, the primary researcher is uniquely well-positioned to disseminate information, but dissemination does not need to be done in isolation.

Conclusion

In summary, the present study provides insight into adolescents with FASD from their perspective and represents an effort to gain a balanced perspective of their lived experiences. In seeking perspectives of adolescents and balancing this inquiry with an exploration of their strengths and struggles, the primary researcher sought to fill a knowledge gap regarding what teachers can do to support adolescents with FASD in the classroom. Exploring ways to disseminate knowledge about FASD to teachers, however, including increasing their understanding of FASD, and finding ways to instill change within classrooms to promote positive outcomes for all adolescents with FASD are some challenges that remain. The present study is a start to examining first-hand adolescent perspectives of FASD, emphasizing strengths not only struggles, and considering what teachers can do to promote positive educational experiences for adolescents with FASD in their classrooms. Researchers can continue to seek to understand the lived experience of adolescents with FASD to promote positive educational experiences for all.

References

- Adams, E. (2016). The joys and challenges of semi-structured interviewing. *Community Practitioner*, 83(7), 18–21.
- Agee, J. (2009). Developing qualitative research questions: A reflective process. *International Journal of Qualitative Studies in Education*, 22(4), 431–437. <https://doi.org/10.1080/09518390902736512>
- Allemang, B., Sitter, K., & Dimitropoulos, G. (2022). Pragmatism as a paradigm for patient-oriented research. *Health expectations: An international journal of public participation in health care and health policy*, 25(1), 38–47. <https://doi.org/10.1111/hex.13384>
- American Psychological Association. (2022). *Thick description*. <https://dictionary.apa.org/thick-description>
- Aspers, P., & Corte, U. (2019). What is qualitative in qualitative research. *Qualitative Sociology*, 42(2), 139–160. <https://doi.org/10.1007/s11133-019-9413-7>
- Bashista, A. E. (2022). Family reflections: Parents and caregivers of people with FASD: What research do we need?. *Pediatric Research*, 1–2. <https://doi.org/10.1038/s41390-021-01926-4>
- Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., N. Reynolds, J., & Racine, E. (2016). It's a shame! Stigma against Fetal Alcohol Spectrum Disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics*, 9(1), 65–77. <https://doi.org/10.1093/phe/phv012>
- Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, 13(1), 68–75. <https://doi.org/10.1177/1744987107081254>
- Blackburn, C., Carpenter, B., & Egerton, J. (2010). Shaping the future for children with Foetal Alcohol Spectrum Disorders. *British Journal of Learning Support*, 25(3), 139–145. <https://doi.org/10.1111/j.1467-9604.2010.01452.x/references>

- Blackburn, C., Carpenter, B., & Egerton, J. (2012) *Educating children and young people with Fetal Alcohol Spectrum Disorders: Constructing Personalised Pathways to Learning*. Routledge.
- Boys, C. J., BJORKE, J., Dole, K. N., Dalnes, C., Terway, S., & Chang, P. (2016). Improving educational outcomes in Fetal Alcohol Spectrum Disorder through interagency collaboration. *Journal of Pediatric Neuropsychology*, 2, 50–57. <https://doi.org/10.1007/s40817-016-0011-2>
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4, 1–8. <https://doi.org/10.1177/2333393617742282>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brenna, B., Burles, M., Holtlander, L., & Bocking, S. (2017). A school curriculum for Fetal Alcohol Spectrum Disorder: Advice from a young adult with FASD. *International Journal of Inclusive Education*, 21(2), 218–229. <https://doi.org/10.1080/13603116.2016.1193565>
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American psychologist*, 32(7), 513. <https://doi.org/10.1037/0003-066X.32.7.513>
- Brown, J. M., Bland, R., Jonsson, E., & Greenshaw, A. J. (2019). A brief history of awareness of the link between alcohol and Fetal Alcohol Spectrum Disorder. *The Canadian Journal of Psychiatry*, 64(3), 164–168. <https://doi.org/10.1177/0706743718777403>
- Brown, N. N., Connor, P. D., & Adler, R. S. (2012). Conduct-disordered adolescents with Fetal Alcohol Spectrum Disorder: Intervention in secure treatment settings. *Criminal Justice & Behavior*, 39(6), 770–793. <https://doi.org/10.1177/0093854812437919>
- Burles, M., Holtlander, L., Bocking, S., & Brenna, B. (2018). Strengths and challenges: A young adult pictures FASD through photovoice. *Review of Disability Studies: An International Journal*, 14(1), 1–20.

- Canada FASD Research Network. (2019). *FASD basic information*. <https://canfasd.ca/wp-content/uploads/2019/11/FASD-Basic-Information.pdf>
- Carlson, J. A. (2010). Avoiding traps in member checking. *The Qualitative Report*, 15(5), 1102–1113. <https://files.eric.ed.gov/fulltext/EJ896214.pdf>
- Carpenter, B. (2011). Pedagogically bereft! Improving learning outcomes for children with Foetal Alcohol Spectrum Disorders. *British Journal of Special Education*, 38(1) 37–43. <https://doi.org/10.1111/j.1467-8578.2011.00495.x>.
- Centre for Addiction and Mental Health. (2022). *Fetal Alcohol Spectrum Disorders (FASD)*. <https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/fetal-alcohol-spectrum-disorder>
- Centres for Disease Control and Prevention. (2022, January 11). *Fetal Alcohol Spectrum Disorders (FASDs)*. <https://www.cdc.gov/ncbddd/fasd/facts.html>
- Chafe, R. (2017). The value of qualitative description in health services and policy research. *Healthcare Policy*, 12(3), 12–18.
- Clarke, V., & Braun, V. (2014) Thematic analysis. In T. Teo (Ed.), *Encyclopedia of Critical Psychology* (pp. 1947-1952). Springer.
- Clarren, S. K., Lutke, J., & Sherbuck, M. (2011). The Canadian guidelines and the interdisciplinary clinical capacity of Canada to diagnose fetal alcohol spectrum disorder. *Journal of Population Therapeutics and Clinical Pharmacology*, 18(3), 494–499.
- Cleversey, K., Brown, J., & Kapasi, A. (2018). Educational services for youth with Fetal Alcohol Spectrum Disorder: Caregivers' perspectives. *International Journal of Mental Health and Addiction*, 16, 1153–1173. <https://doi.org/10.1007/s11469-017-9838-8>
- Cohen, L., Manion, L., & Morrison, K. (2018). *Research methods in education* (8th ed.). Routledge.

- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE Publications, Inc.
- DeJonckheere M, & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: A balance of relationship and rigour. *Family Medicine and Community Health*, 7, 1–8. <https://doi.org/10.1136/fmch-2018-000057>
- Doyle, S. (2007). Member checking with older women: A framework for negotiating meaning. *Health Care for Women International*, 28(10), 888–908. <https://doi.org/10.1080/07399330701615325>
- Doyle, L., McCabe, C., Keogh, B., Brady, A., & McCann, M. (2020). An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing*, 25(5), 443–455. <https://doi.org/10.1177/1744987119880234>
- Duquette, C., & Stodel, E. J. (2005). School experiences of students with Fetal Alcohol Spectrum Disorder. *Exceptionality Education Canada*, 15(2), 51–75.
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006). Persistence in high school: Experiences of adolescents and young adults with Fetal Alcohol Spectrum Disorder. *Journal of Intellectual & Developmental Disability*, 31(4), 219–231. <https://doi.org/10.1080/13668250601031930>
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2007). Secondary school experiences of individuals with Foetal Alcohol Spectrum Disorder: Perspectives of parents and their children. *International Journal of Inclusive Education*, 11(5-6), 571–591. <https://doi.org/10.1080/13603110600668611>
- Dybdahl, S., & Ryan, S. (2009). Inclusion for students with Fetal Alcohol Syndrome: Classroom teachers talk about practice. *Preventing School Failure: Alternative Education for Children and Youth*, 53(3), 185–196. <https://doi.org/10.3200/PSFL.53.3.185-196>
- Edmonds, K., & Crichton, S. (2008). Finding ways to teach students with FASD: A research study. *International Journal of Special Education*, 23(1), 54–73.

- Flannigan, K., Wrath, A., Ritter, C., McLachlan, K., Harding, K. D., Campbell, A., Reid, D., & Pei, J. (2021a). Balancing the story of Fetal Alcohol Spectrum Disorder: A narrative review of the literature on strengths. *Alcoholism: Clinical and Experimental Research*, *45*, 2448–2464. <https://doi.org/10.1111/acer.14733>
- Flannigan, K., Kapasi, A., Pei, J., Murdoch, I., Andrew, G., & Rasmussen, C. (2021b). Characterizing adverse childhood experiences among children and adolescents with prenatal alcohol exposure and Fetal Alcohol Spectrum Disorder. *Child Abuse & Neglect*, *112*, 1–15. <https://doi.org/10.1016/j.chiabu.2020.104888>
- Galletta, A. (2013). *Mastering the semi-structured interview and beyond: From research design to analysis and publication*. NYU Press.
- Government of Canada. (2018). *Tri-council policy statement: Ethical conduct for research involving humans – TCPS 2*. <https://ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf>
- Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. SAGE Publications, Inc.
- Guy-Evans, O. (2020, November 9). Bronfenbrenner's Ecological Systems Theory. *SimplyPsychology*. <https://www.simplypsychology.org/Bronfenbrenner.html>
- Holmes, A. (2020). Researcher positionality - A Consideration of its influence and place in qualitative research - A new researcher guide. *Shanlax International Journal of Education*, *8*(4), 1–10. <https://doi.org/10.34293/education.v8i4.3232>
- Jamshed, S. (2014). Qualitative research method-interviewing and observation. *Journal of Basic and Clinical Psychology*, *5*(4), 87–88. <https://doi.org/10.4103/0976-0105.141942>
- Kable, J. A., O'Connor, M. J., Olson, H. C., Paley, B., Mattson, S. N., Anderson, S. M., & Riley, E. P. (2016). Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE): Proposed DSM-5 diagnosis. *Child Psychiatry and Human Development*, *47*(2), 335–346. <https://doi.org/10.1007/s10578-015-0566-7>

- Kaushik, V., Walsh, C. A., & Lai, D. W. L. (2019). Pragmatism as a research paradigm and its implications for social work research. *Social Sciences*, 8(9), 1–17. <https://doi.org/10.3390/socsci8090255>
- Kingdon, D., Cardoso, C., & McGrath, J. J. (2016). Research review: Executive function deficits in Fetal Alcohol Spectrum Disorders and Attention-deficit/Hyperactivity Disorder - a meta-analysis. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 57(2), 116–131. <https://doi.org/10.1111/jcpp.12451>
- Kippin, N. R., Leitão, S., Watkins, R., Finlay-Jones, A., Condon, C., Marriott, R., Mutch, R. C., & Bower, C. (2018). Language diversity, language disorder, and Fetal Alcohol Spectrum Disorder among youth sentenced to detention in Western Australia. *International Journal of Law and Psychiatry*, 61, 40–49. <https://doi.org/10.1016/j.ijlp.2018.09.004>
- Kleinfeld, J., & Westcott, S. (Eds.). (1993). *Fantastic Antone succeeds: Experiences in educating children with Fetal Alcohol Syndrome*. University of Alaska Press.
- Koch, T. (1994). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19(5), 976–986. <https://doi.org/10.1111/j.1365-2648.1994.tb01177.x>
- Kully-Martens, K., McNeil, A., Pei, J., & Rasmussen, C. (2022). Toward a strengths-based cognitive profile of children with Fetal Alcohol Spectrum Disorders: Implications for intervention. *Current Developmental Disorders Reports*, 9(2), 53-62. <https://doi.org/10.1007/s40474-022-00245-5>
- Lange, S., Probst, C., Gmel, G., Rehm, J., Burd, L., & Popova, S. (2017). Global prevalence of Fetal Alcohol Spectrum Disorder among children and youth: A systematic review and meta-analysis. *JAMA Pediatrics*, 171(10), 948–956. <https://doi.org/10.1001/jamapediatrics.2017.1919>
- Lavrakas, P. J. (2008). Purposive sample. In *Encyclopedia of survey research methods* (Vol. 1, pp. 645–647). SAGE Publications, Inc. <https://dx.doi.org/10.4135/9781412963947.n419>
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications, Inc.

- Lutherwood. (2021, April 23). *FASD & educational accommodations* [Video]. YouTube.
<https://www.youtube.com/watch?v=H00e3gXFnFs&t=64s>
- Lynch, M. E., Kable, J. A., & Coles, C. D. (2015). Prenatal alcohol exposure, adaptive function, and entry into adult roles in a prospective study of young adults. *Neurotoxicology and Teratology*, *51*, 52–60. <https://doi.org/10.1016/j.ntt.2015.07.008>
- Makela, M. L., Pei, J. R., Kerns, K. A., MacSween, J. V., Kapasi, A., & Rasmussen, C. (2019). Teaching children with Fetal Alcohol Spectrum Disorder to use metacognitive strategies. *The Journal of Special Education*, *53*(2), 119–128. <https://doi.org/10.1177/0022466919832371>
- Mallinckrodt, B., Miles, J. R., & Levy, J. J. (2014). The scientist-practitioner-advocate model: Addressing contemporary training needs for social justice advocacy. *Training and Education in Professional Psychology*, *8*(4), 303–311. <https://doi.org/10.1037/tep0000045>
- Mandolesi, L., Polverino, A., Montuori, S., Foti, F., Ferraioli, G., Sorrentino, P., & Sorrentino, G. (2018). Effects of physical exercise on cognitive functioning and wellbeing: Biological and psychological benefits. *Frontiers in psychology*, *9*, 1–11. <https://doi.org/10.3389/fpsyg.2018.00509>
- Mariasine, J., Pei, J., Poth, C. A., Henneveld, D., & Rasmussen, C. (2014) Adaptive functioning, social skills, mental health, and personal strengths among adolescents with prenatal alcohol exposure (PAE). *International Journal of Psychological Studies*, *6*(2), 36–48. <https://doi.org/10.5539/ijps.v6n2p36>
- Mauthner, N. S., & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, *37*(3), 413–431. <https://doi.org/10.1177/00380385030373002>
- McGrath, C., Palmgren, P. J. & Liljedahl, M. (2019) Twelve tips for conducting qualitative research interviews. *Medical Teacher*, *41*(9), 1002–1006. <https://doi.org/10.1080>

/0142159X.2018.1497149

- McIntosh, M. J., & Morse, J. M. (2015). Situating and constructing diversity in semi-structured interviews. *Global Qualitative Nursing Research*, 2, 1–12. <https://doi.org/10.1177/2333393615597674>
- McLachlan, K., Flannigan, K., Temple, V., Unsworth, K., & Cook, J. L. (2020). Difficulties in daily living experienced by adolescents, transition-aged youth, and adults with Fetal Alcohol Spectrum Disorder. *Alcoholism: Clinical and Experimental Research*, 44(8), 1609–1624. <https://doi.org/10.1111/acer.14385>
- Memos and memoing. (2008). In Given, L. M. (Ed.), *The SAGE encyclopedia of qualitative research methods* (1st ed., Vol. 1–2, pp. 505–506). SAGE Publications, Inc.
- Mikuska, E. (Academic). (2018). *The importance of pilot studies* [Video]. SAGE Research Methods. <https://www-doi-org.login.ezproxy.library.ualberta.ca/10.4135/9781526450180>
- Millans, M. N. (2015). Educational needs and care of children with FASD. *Current Developmental Disorders Reports*, 2, 210–218. <https://doi.org/10.1007/s40474-015-0055-5>
- Millar, J. A., Thompson, J., Schwab, D., Hanlon-Dearman, A., Goodman, D., Koren, G., & Masotti, P. (2017). Educating students with FASD: Linking policy, research, and practice. *Journal of Research in Special Educational Needs*, 17(1), 3–17. <https://doi.org/10.1111/1471-3802.12090> – 2014 article?
- Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice*, 24(1), 9–18. <https://doi.org/10.1080/13814788.2017>
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16, 1–13. <https://doi.org/10.1177/1609406917733847>

- Odishaw, J., & Snart, F. (2005). Assessment of cognitive processing in persons with FASD: A promising alternative to traditional IQ measures. *Exceptionality Education Canada*, 15(1), 25–41.
- Pacer Center, Inc. (2020). *Student action plan against bullying*. <https://pacer.org/publications/bullypdf/BP-25.pdf>
- Pei, J., Denys, K., Hughes, J., & Rasmussen, C. (2011). Mental health issues in Fetal Alcohol Spectrum Disorder. *Journal of Mental Health*, 20(5), 438–448. <https://doi.org/10.3109/09638237.2011.577113>
- Pei, J., Job, J., Poth, C., O'Brien-Langer, A., & Tang, W. (2015). Enhancing learning environments for students affected by Fetal Alcohol Spectrum Disorders: An exploratory study of Canadian pre-service teacher knowledge and conceptions. *Journal of Educational and Training Studies*, 3(5), 134–143. <https://doi.org/10.11114/jets.v3i5.955>
- Petrenko, C. L. (2015). Positive behavioral interventions and family support for Fetal Alcohol Spectrum Disorders. *Current Developmental Disorders Reports*, 2(3), 199–209. <https://doi.org/10.1007/s40474-015-0052-8>
- Petrenko, C. L., Tahir, N., Mahoney, E. C., & Chin, N. P. (2014). Prevention of secondary conditions in Fetal Alcohol Spectrum Disorders: Identification of systems-level barriers. *Maternal and Child Health Journal*, 18(6), 1496–1505. <https://doi.org/10.1007/s10995-013-1390-y>
- Pettenger, M., West, D., & Young, N. (2014). Assessing the impact of role play simulations on learning in Canadian and US classrooms. *International Studies Perspectives*, 15(4), 491–508. <http://doi.org/10.1111/insp.12063>
- Pope, D. C. (Academic). (2017). *Introduction to qualitative research methods* [Video]. SAGE Research Methods. <https://methods.sagepub.com/video/introduction-to-qualitative-research-methods>

- Popova, S., Lange, S., Burd, L., Nam, S., & Rehm, J. (2016a) Special education of children with Fetal Alcohol Spectrum Disorder. *Exceptionality*, 24(3), 165–175. <https://doi.org/10.1080/09362835.2015.1064415>
- Popova, S., Lange, S., Poznyak, V., Chudley, A. E., Shield, K. D., Reynolds, J N., Murray, M., & Rehm, J. (2019). Population-based prevalence of Fetal Alcohol Spectrum Disorder in Canada. *BMC Public Health*, 19, 1–12. <https://doi.org/10.1186/s12889-019-7213-3>
- Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R., Bekmuradov, D., & Rehm, J. (2016b). Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis. *Lancet*, 387(10022), 978–987. [https://doi.org/10.1016/S0140-6736\(15\)01345-8](https://doi.org/10.1016/S0140-6736(15)01345-8)
- Poth, C., Pei, J., Job, J. M., & Wyper, K. (2014). Toward intentional, reflective, and assimilative classroom practices with students with FASD. *The Teacher Educator*, 49(4), 247–264. <https://doi.org/10.1080/08878730.2014.908888>
- QSR International. (2022). *NVivo qualitative data analysis*. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Ritchie, J., & Lewis, J. (Eds.). (2003). *Qualitative research practice: A guide for social science students and researchers*. SAGE publications, Inc.
- Rogers, B. J., McLachlan, K., & Roesch, R. (2013). Resilience and enculturation: Strengths among young offenders with Fetal Alcohol Spectrum Disorder. *First Peoples Child & Family Review*, 8(1), 62-80. <https://doi.org/10.7202/1071407ar>
- Sanders, J., & Buck, G. H. (2010). A long journey: Biological and non-biological parents' experiences raising children with FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, 17(2), 308–322.
- Simon, J., Porterfield, P., Bouchal, S. R., & Heyland, D. (2015). 'Not yet' and 'Just ask': Barriers and facilitators to advance care planning--a qualitative descriptive study of the

- perspectives of seriously ill, older patients and their families. *BMJ Supportive & Palliative Care*, 5(1), 54–62. <https://doi.org/10.1136/bmjspcare-2013-000487>
- Skorka, K., Copley, J., McBryde, C., Meredith, P. J., & Reid, N. (2022). Lived experiences of adolescents with Fetal Alcohol Spectrum Disorder. *Developmental Medicine and Child Neurology*, 10.1111/dmcn.15290. Advance online publication. <https://doi.org/10.1111/dmcn.15290>
- Skorka, K., McBryde, C., Copley, J., Meredith, P. J., & Reid, N. (2020). Experiences of children with Fetal Alcohol Spectrum Disorder and their families: A critical review. *Alcoholism: Clinical and Experimental Research*, 44(6), 1175–1188. <https://doi.org/10.1111/acer.14335>
- Spriggs, A. L., Iannotti, R. J., Nansel, T. R., & Haynie, D. L. (2007). Adolescent bullying involvement and perceived family, peer and school relations: Commonalities and differences across race/ethnicity. *The Journal of Adolescent Health*, 41(3), 283–293. <https://doi.org/10.1016/j.jadohealth.2007.04.009>
- Stade, B., Beyene, J., Buller, K., Ross, S., Patterson, K., Stevens, B., Sgro, M., Ungar, W., Watson, W., & Koren, G. (2011). Feeling different: The experience of living with Fetal Alcohol Spectrum Disorder. *Journal of Population Therapeutics and Clinical Pharmacology*, 18(3), 475–485.
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. *Journal of Developmental and Behavioral Pediatrics*, 25(4), 228–238. <https://doi.org/10.1097/00004703-200408000-00002>
- The Alberta FASD Cross Ministry Committee. (2020). *The FASD patient journey*. https://edmontonfetalalcoholnetwork.org/wp-content/uploads/2020/07/FASD-Patient-Journey_v8.pdf

- Timler, G. R., & Olswang, L. B. (2001). Variable structure/ variable performance: Parent and teacher perspectives on a school-age child with FAS. *Journal of Positive Behavior Interventions*, 3(1), 48–56. <https://doi.org/10.1177/109830070100300107>
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, 48, 388–396. <https://doi.org/10.1111/j.1365-2648.2004.03207.x>
- Varigonda, A. L., Edgcomb, J. B., & Zima, B. T. (2020). The impact of exercise in improving executive function impairments among children and adolescents with ADHD, Autism Spectrum Disorder, and Fetal Alcohol Spectrum Disorder: A systematic review and meta-analysis. *Archives of Clinical Psychiatry*, 47(5), 146–156. <https://doi.org/10.1590/0101-60830000000251>
- Wilhoit, L. F., Scott, D. A. & Simecka, B. A. (2017). Fetal Alcohol Spectrum Disorders: Characteristics, complications, and treatment. *Community Mental Health Journal*, 53, 711–718. <https://doi.org/10.1007/s10597-017-0104-0>
- Willis, D. G., Sullivan-Bolyai, S., Knafel, K., & Cohen, M. Z. (2016). Distinguishing features and similarities between descriptive phenomenological and qualitative description research. *Western Journal of Nursing Research*, 38(9), 1185–1204. <https://doi.org/10.1177/0193945916645499>
- World Health Organization. (2022). *Adolescent health*. https://www.who.int/health-topics/adolescent-health/#tab=tab_1
- Wozniak, J. R., Riley, E. P., & Charness, M. E. (2019). Clinical presentation, diagnosis, and management of Fetal Alcohol Spectrum Disorder. *Lancet Neurol*, 18(8), 760–770. [https://doi.org/10.1016/S1474-4422\(19\)30150-4s](https://doi.org/10.1016/S1474-4422(19)30150-4s)

Appendix A

Information Letter and Consent Form

Faculty of Education
Department of Educational Psychology

Study Title: *What I Want My Teachers to Know:
The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Research Investigator:

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Supervisor:

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Background:

You are being asked to give consent for your child to participate in this study. If you agree, we will get their contact information from you later. The results of this study will be used for my Master's thesis. At a later date, general research findings may be made available. Before you decide if your child should participate, I will go over this form with you. You are welcome to ask questions, and you will get a copy of this form.

Purpose:

Fetal Alcohol Spectrum Disorder (FASD) research has focused on deficits, but students with FASD have many strengths in and out of the classroom. In effect, we will conduct interviews with youth who have FASD. By conducting these interviews, we hope to extend current understandings beyond educator and caregiver reports. We also hope to learn more about the unique perspective of the youth themselves. Moreover, we want to learn about these students' strengths and weaknesses in and out of school settings.

Study Procedures:

First, you will receive a short Google Form questionnaire. A link to the Google Form will be sent by email, and the Google Form will ask about your child. This should take around 10 minutes to complete, but it may take more or less time depending on the detail in your responses. Next, if your child is eligible for the study and you decide you want your child to participate, I will obtain your consent. I expect the consent process to take no longer than 30 minutes. Finally, I will contact the participant by email and arrange a virtual interview time.

I will review research goals and participant tasks with your child. They will have two options to choose from. They can think it over and let me know at a later time if they do or do not want to participate in the study. Or, they can participate in a short interview immediately following the review of study goals and tasks.

If they agree to an interview, I will ask them eight questions. Two questions will be about their age and the province they live in. All other questions will relate to when they did or did not have success in three settings (i.e., home, school, and community). The interview will last about 1 hour, but it could take more or less time. Interviews will be held over Google Meet and recorded. Cameras should be turned off so only audio is logged. Only your child and the researcher will

participate in the interview. Your child will be required to attend the interview at the agreed upon time. If something changes, 24-hour notice should be given, if possible.

Later in the study, I will contact your child via email again and offer them a chance for an optional follow-up interview. If they choose to participate, I will review general, core themes collected across all interviews. This will ensure I am accurately representing the voice of adolescents with FASD. Follow-up interviews may be as short as 5 to 10 minutes or they may last for around 30 minutes.

Benefits:

As a parent or guardian, you will likely not benefit from this study, but the participant may benefit. Adolescents with FASD will have their strengths recorded, and their stories will be told from their point of view. By doing this study, teachers will be able to provide quality support for students with FASD. Teachers will also learn more about strengths adolescents with FASD have to offer. Society could gain more knowledge of those who have FASD too. It is also possible participants will not benefit from this study.

Risks:

Some risks exist. Participants may become tired. They will be using a computer for about 1 hour. They may also have minor distress due to discussing weaknesses, which could lead to strong feelings. In addition, participants may have fatigue because interviews require the ability to focus and pay attention.

Due to computer use, during the interview participants can take breaks. Participants will also be reminded to take breaks if they experience fatigue. To reduce any distress, they could feel when talking about weaknesses, they will be encouraged to share only what they are comfortable with, and they will be reminded that they can stop sharing at any time. A prompt about taking breaks will be provided before the interview. Two verbal prompts about taking breaks will be provided during the interview.

Some risks may not be known. If I learn of anything that may affect your child's ability to continue, I will stop the interview and let you know. If the participant requires support after the interview, help is available: <https://www.cbc.ca/radio/opp/if-you-want-to-talk-to-someone-here-s-a-list-of-resources-that-might-help-1.4603730>. This could help you find supports in your area.

Voluntary Participation:

The participant does not have to participate. Participation is voluntary. They do not need to answer any specific questions even if participating in the study. They can opt out without penalty. They can ask to have data withdrawn and not included.

Even if they agree to be in the study, they can change their mind. They can withdraw at any time. Two weeks after the interview the data will be anonymized, so it will no longer be possible to track data back to the participant. After this time, their data can no longer be removed. If the participant opts out before the end of the interview, or emails me within two weeks following the interview to tell me they want to remove their data, I will not use the data we have, and the data will be deleted.

Confidentiality & Anonymity:

This research is for my Master's project, but it may be used in articles or presentations. It may also be used in teaching activities. Participants will not be identified in any of these. Data will be kept private, and only my Research Supervisor and I will access the data. Data will be kept in a

secure place for a minimum of 5 years after the first publication, and data will be secured with a password.

If you or your child would like a report of the findings, please email me at the end of the study (i.e., April 2022) for more information. I may also use data I get from this study in future research, but if I do this it will have to be approved by a Research Ethics Board.

Absolute confidentiality may not be possible at all times. I am legally obligated to report evidence of child abuse or neglect. Should the adolescent indicate intent to harm themselves and/or others, I am also legally required to report to this.

Contact Information:

If you have any further questions regarding this study, please contact Vanessa Boila at boila@ualberta.ca.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers.

Consent Statement:

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I acknowledge that I have received a copy of this consent form.

At this time, please let me know if you (a) agree to the above information, and (b) want your child to participate in this study.

Consent Confirmation

Consent provided by (name of parent(s)/guardian(s)):

Name of participant:

Consent obtained by (name of researcher):

Consent obtained on (list date):

Consent obtained at (list time):

Appendix B

Assent Form

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Research Investigator:

Vanessa Boila, B.F.A., B.Ed., B.A. (Hons.)
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What is a research study?

A research study is a way to find out new information about something. People do not need to be in a research study if they don't want to.

Why are you being asked to be part of this research study?

You are being asked to take part in this research study because we are trying to learn more about adolescents with Fetal Alcohol Spectrum Disorder (FASD). We want to find out what adolescents with FASD want to tell teachers about what they are good at and what they struggle with at home, in school, and in the community.

We are asking you to be in the study because your parents or guardians have indicated that you meet the study criteria. At least 10 or more adolescents between the ages of 14 to 17 are expected to be in this study.

If you join the study what will happen to you?

We want to tell you about some things that will happen to you if you are in this study. First, you will meet the researcher on Google Meet, and you will confirm that you agree to be in the study. Once the study begins, you will be in the study for about 1 hour. Next, we will encourage you to turn off your video camera or web camera, if you have one, so only your voice is recorded during the study.

After you've had a chance to turn your camera off, you will talk with a researcher about some things. We will ask you to answer questions about what you want teachers to know about your FASD diagnosis, and you will get to tell them all about the things you are good at and the things you struggle with. We will also talk about different places such as your home environment, school settings, and the communities you belong to. Your parents or guardians will not participate in the interview with you.

Later in the study, the researcher will email you again to offer a chance for a short (i.e., around 30 minutes or less), optional follow-up interview on Google Meet. If you want to do this, the researcher will review general information collected from prior interviews to ensure they are correctly interpreting information shared by adolescents with FASD.

Will any part of the study hurt?

You will be using your computer for about 1 hour, so you might get tired or have a hard time focusing. Some questions will require you to think about your struggles and weaknesses, so you may experience some strong emotions or thoughts.

Will the study help you?

This study will allow you to tell us your thoughts and ideas from your perspective rather than asking your parents or guardians to tell us about you. As well, you will get to talk all about the things you do really well or that you are good at. It's possible that study might not have any benefits for you.

Will the study help others?

This study might find out things that will help other adolescents with FASD someday. Also, the study might help teachers recognize the strengths adolescents with FASD have. Additionally, this study might help teachers, so they can make learning easier or more enjoyable for adolescents with FASD. Finally, it's possible this study might not have any benefits for others.

Do you have to be in the study?

You do not have to be in the study. It's up to you. No one will be upset if you don't want to do this study. If you join the study, you can change your mind and stop being part of it at any time. All you have to do is tell me. It's okay. If you do want to be in this study and you choose to participate, after we are done with an interview, you will have up to two weeks to tell me if you want your data to be removed. No matter what you decide to do, the researchers and your parents or guardians won't be upset.

What choices do you have if you say no to this study?

This study is extra, so if you don't want to do it that is okay. If you do not want to participate, there are no other choices available.

Do your parents or guardians know about this study?

This study was explained to your parents or guardians and they said that we could ask you if you want to be in it. You can talk this over with them before you decide.

Who will see the information collected about you?

The information collected about you during this study will be kept secure. Nobody will know it except the people doing the research. The study information about you will not be given to your parents or your teachers, and researchers will not tell your friends or anyone else. We will only reveal general information about the research findings to your parent or guardian if they have asked us for it.

However, if you tell me you might be a danger to yourself or others (e.g., you are thinking about harming yourself or someone else), I will need to tell your parent(s)/guardian(s). If you tell me about abuse or neglect (not caring for you properly), I will need to tell the appropriate authorities (e.g., police).

What if you have any questions?

You can ask any questions that you may have about the study. If you have a question later that you didn't think of now, either you can email me or have your parents or guardians email me at boila@ualberta.ca.

Other information about the study:

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers.

You will receive an electronic copy of this paper to keep. If you want to be in the study and do not want to talk this decision over with your parents or guardians, we can begin the study now. If you would like to talk this over with your parents or guardians before deciding to participate then you can do that. If you do not want to participate at all, that is another option. At this time, please let me know what you have decided.

Assent Confirmation

Consent provided by (name of parent(s)/guardian(s)):

Assent provided by (name of participant):

Assent obtained by (name of researcher):

Assent obtained on (list date):

Assent obtained at (list time):

Appendix C

Recruitment Flyer

Now recruiting adolescents with FASD for a Canada-wide virtual research study!

Study Title: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

We are conducting a study examining what adolescents with Fetal Alcohol Spectrum Disorder (FASD) want teachers to know about the strengths they have and the struggles they experience at home, in school settings, and within the community.

Who can participate?

Individuals with a FASD diagnosis who are between the ages of 14–17 years old, are Canadian citizens, have access to a home computer with an external or built-in microphone, can use this technology as well as Google Meet independently, can provide their own accommodations if needed (e.g., text enlargement), can verbally respond to questions, and can sit for an hour-long interview (with or without a few short breaks in between).

What is involved?

Parents or legal guardians will review consent individually as well as with the Research Investigator over Google Meet. If consent is given, the adolescent with FASD will review the study requirements with the Principal Researcher over Google Meet. If the adolescent wants to participate, they will take part in a virtual interview with the Principal Researcher. Parents or guardians will not be invited to the interview because their presence may affect the information that is shared. Participants will respond to six main questions during the interview. Additional questions may be asked if or when clarification is needed. Later in the study, an opportunity for an optional follow-up interview will be provided, so participants can review general themes identified during the study to ensure they accurately reflect the lived experiences of adolescents with FASD.

What are the potential risks?

Adolescents may experience physical or psychological fatigue due to computer use, the questions being asked of them, or the need to stay focused for an extended period of time. They may also experience minor psychological or emotional distress because they are being asked to discuss some of their actual or perceived weaknesses and struggles.

How long does it take?

The parent/guardian meeting is expected to take no longer than 30 minutes. Participant interviews will take around 1 hour.

Who are the researchers?

Vanessa Boila (Researcher Investigator, Graduate Student), and Dr. Jacqueline Pei (Faculty Supervisor).

What if I have questions?

Please contact the Research Investigator, Vanessa Boila, at boila@ualberta.ca.

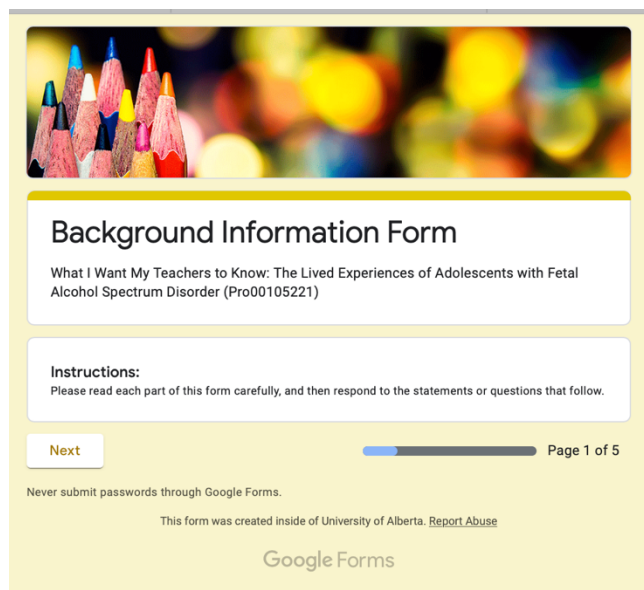
How can my child participate?

If you are the parent or legal guardian of an adolescent who meets the criteria outlined above, please email Vanessa Boila at boila@ualberta.ca to express your interest.

Note: The ethics protocol for this project was reviewed and cleared by the University of Alberta Research Ethics Board. If you have any questions about your rights as a research participant or how the research is being conducted, you may contact the Research Ethics Office at (780) 492-2615.

Appendix D

Background Information Form



Background Information Form
* Required

What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder (Pro00105221)

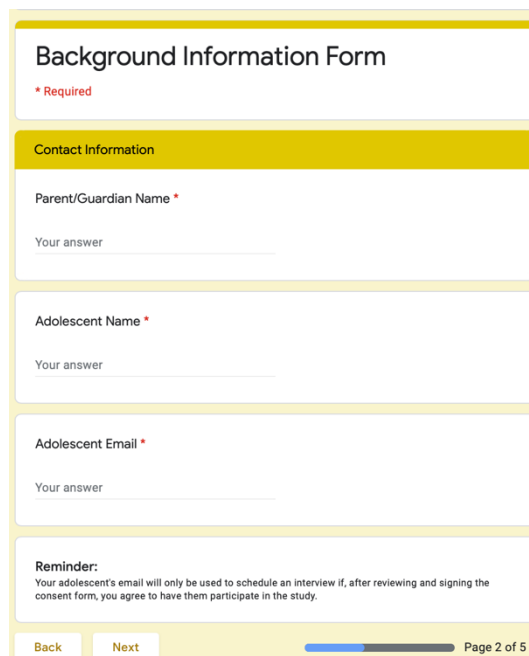
Instructions:
Please read each part of this form carefully, and then respond to the statements or questions that follow.

Next Page 1 of 5

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Google Forms

1



Background Information Form
* Required

Contact Information

Parent/Guardian Name *
Your answer _____

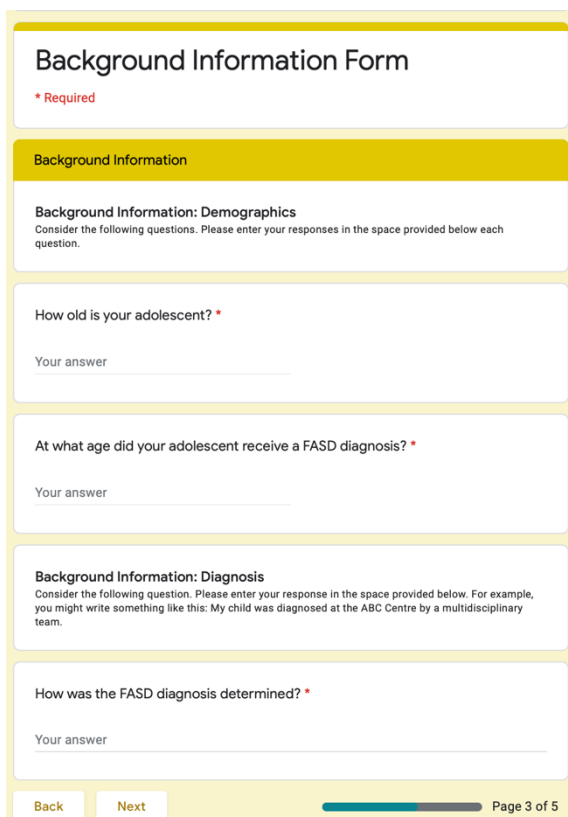
Adolescent Name *
Your answer _____

Adolescent Email *
Your answer _____

Reminder:
Your adolescent's email will only be used to schedule an interview if, after reviewing and signing the consent form, you agree to have them participate in the study.

Back **Next** Page 2 of 5

2



Background Information Form
* Required

Background Information

Background Information: Demographics
Consider the following questions. Please enter your responses in the space provided below each question.

How old is your adolescent? *
Your answer _____

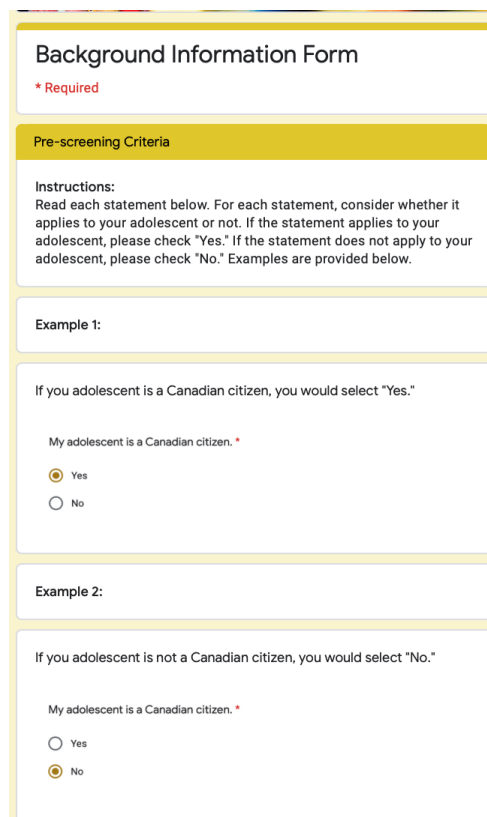
At what age did your adolescent receive a FASD diagnosis? *
Your answer _____

Background Information: Diagnosis
Consider the following question. Please enter your response in the space provided below. For example, you might write something like this: My child was diagnosed at the ABC Centre by a multidisciplinary team.

How was the FASD diagnosis determined? *
Your answer _____

Back **Next** Page 3 of 5

3



Background Information Form
* Required

Pre-screening Criteria

Instructions:
Read each statement below. For each statement, consider whether it applies to your adolescent or not. If the statement applies to your adolescent, please check "Yes." If the statement does not apply to your adolescent, please check "No." Examples are provided below.

Example 1:

If you adolescent is a Canadian citizen, you would select "Yes."

My adolescent is a Canadian citizen. *
 Yes
 No

Example 2:

If you adolescent is not a Canadian citizen, you would select "No."

My adolescent is a Canadian citizen. *
 Yes
 No

4

Instructions:
Read each statement below. For each statement, consider whether it applies to your adolescent or not. If the statement applies to your adolescent, please check "Yes."

My adolescent is a Canadian citizen. *

Yes
 No

My adolescent has access to a computer with an external microphone or built-in microphone. *

Yes
 No

My adolescent can use technology, including Google Meet, independently. *

Yes
 No

5

My adolescent can provide their own accommodations if needed (e.g., text enlargement). *

Yes
 No

My adolescent can respond to questions verbally (with words). *

Yes
 No

My adolescent can sit for a 1-hour interview with or without breaks. *

Yes
 No

[Back](#) [Next](#) Page 4 of 4

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Google Forms

6

Background Information Form

Thank you!

You have completed the Background Information Form. Remember to click the "Submit" button below. If you have questions, please email boila@ualberta.ca.

[Back](#) [Submit](#) Page 5 of 5

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Google Forms

7

Appendix E

Interview Questions Preview

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Interview Questions Preview

Beginning Questions

1. How old are you?
2. What province do you live in?

Home Contexts

3. First, I want you to think about the place you live in such as a house or apartment. When does the day go well for you in this place?
4. Next, I want you to think about the place you live in again. When does the day not go well for you in this place?

School Contexts

5. Next, I want you to think about being at school. When does the day go well for you in this place?
6. Next, I want you to think about being at school again. When does the day not go well for you in this place?

Community Contexts

7. Next, I want you to think about a community you belong to or a community activity you do. This might be a group of people you spend time with outside of school, such as a sports team, arts-and-crafts group, or video-game group, a place such as a church or a pet store, or an activity you do outside of school such as shopping. When does the day go well for you with this group, in this place, or during this activity?
8. Finally, I want you to think about the community you belong to again. When does the day not go well for you with this group, in this place, or during this activity?

Ending Question

9. Do you have any questions for me?
10. Would you like to tell me anything else

Appendix F

Interview Timeline

Faculty of Education
Department of Educational Psychology

Interview Timeline

(to be used to facilitate the virtual participant interview)

DURATION (MINUTES)	TASK
10	INTRODUCTION
10	<p>Review and obtain assent.</p> <p>Explain check ins and interview structure.</p> <p>Ask two demographic questions:</p> <ol style="list-style-type: none"> 1) How old are you? 2) What province do you live in?
15	QUESTIONS (HOME FOCUS)
5	Question 1 – When does the day go well for you in this place?
5	Question 2 – When does the day not go well for you in this place?
5	Check in with participants to see if they need to take a break or if they have any questions.

15	QUESTIONS (SCHOOL FOCUS)
5	Question 3 – When does the day go well for you in this place?
5	Question 4 – When does the day not go well for you in this place?
5	Check in with participants to see if they need to take a break or if they have any questions.
15	QUESTIONS (COMMUNITY FOCUS)
5	Question 5 – When does the day go well for you with this group, in this place, or during this activity?
5	Question 6 – When does the day not go well for you with this group, in this place, or during this activity?
5	CONCLUSION
5	Remind participants about ability to withdraw data for up to two weeks following the interview, the option of a follow-up interview, and ask if they have any remaining questions.
60	

Appendix G

Interview Script

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Interview Script

(to be used to facilitate the virtual participant interview)

R = Researcher

P = Participant

R: Thank you for joining. My name is Vanessa. I'm a student at the University of Alberta, and I'm going to be spending some time online with you today. Before we begin, please turn on your microphone. Also, please turn off your camera if you have one on your computer.

P: *(Turns microphone on and turns camera off).*

R: Prior to this meeting, I emailed you a two-page form for you to read through or look at. I'm going to read through the form right now, and I'm going to explain each section in my own words. Feel free to ask me questions after I'm done. *(Reads form and clarifies each section).* Do you have any questions?

P: *(Asks questions if they have any).*

R: Okay, great. You have a choice to make now. You can think more about this form and if you want to participate, and then you can let me know on another day if you still want to do the study or not. If you choose this option, we will not be able to do the interview today. Or, for your other choice, you can let me know you want to participate today and we can continue with the interview right now. Would you like to think it over or do the interview?

R (option 1 – think it over): Okay, thanks for letting me know that you want to think more about this study and if you want to participate or not. Once you've made your decision, please email me to let me know what you have decided. If you still want to participate, we can reschedule the interview. I will end the meeting now. Have a great day. Bye.

R (option 2 – start right now): Okay, thanks for letting me know. We're almost ready to start the interview. I want to tell you that if you need to take a break during the interview, please let me know. Also, I want to remind you to only share what you feel comfortable sharing. Let's get started now. This interview should take just under an hour, but it may take longer depending on your responses and if you would like to take some breaks throughout. I'm going to ask you some questions. I have eight questions I want to ask you, but as I listen to your responses, I may ask you more questions.

R: First, I want to know a little more about you. How old are you

P: *(Gives their response)*.

R: Thanks. What province do you live in?

P: *(Gives their response)*.

R: Great, thanks for answering those two questions about yourself. Now I have six main questions I am going to ask. First, I want you to think about the place you live in such as a house or apartment. When does the day go well for you in this place?

P: *(Gives their response)*.

R: Thank you for sharing. Next, I want you to think about the place you live in again. When does the day not go well for you in this place?

P: *(Gives their response)*.

R: Thank you for sharing. I want to check in with you right now. Do you have any questions for me? Do you need to take a short 5-minute break?

P: *(Asks questions and/or takes a short break if they need or want it)*.

R: Next, I want you to think about being at school. When does the day go well for you in this place?

P: *(Gives their response)*.

R: Thank you for sharing. Next, I want you to think about being at school again. When does the day not go well for you in this place?

P: *(Gives their response)*.

R: Thank you for sharing. I want to check in with you again. Do you have any questions for me? Do you need to take a short 5-minute break?

P: *(Asks questions and/or takes a short break if they need or want it)*.

R: Next, I want you to think about a community you belong to or a community activity you do. This might be a group of people you spend time with outside of school, such as a sports team, arts-and-crafts group, or video-game group, a place such as a church or a pet store, or an activity you do outside of school such as shopping. When does the day go well for you with this group, in this place, or during this activity?

P: *(Gives their response)*.

R: Thank you for sharing. Finally, I want you to think about the community you belong to again. When does the day not go well for you with this group, in this place, or during this activity?

P: *(Gives their response)*.

R: Thank you for sharing. You've answered all of the questions I wanted to ask you today. We are done with our interview. Thank you for participating in this study. Your participation is greatly appreciated. Before we end our online meeting today, I just have two more things to talk with you about.

First, if you want to remove your data from this study, please let me know now or within the next two weeks. If you send me an email in the next two weeks and you tell me to remove your data, I can take it out of the study. After two weeks, I will no longer be able to figure out if the responses I've collected belong to you or another person.

Second, I will email you again later in the study to offer you another interview. The follow-up interview is optional, which means you do not have to do it if you do not want to. At the next interview, I will talk about general ideas adolescents with FASD shared with me because I want to make sure I understand the information adolescents with FASD told me.

Do you have any questions for me? Would you like to tell me anything else?

P: *(Gives their response)*.

R: Great, thank you for letting me know. You can now exit the meeting. Have a great day.

Appendix H

Procedural Overview

Step 1: Participant Recruitment

- (a) Parent(s)/guardian(s) see/receive the Recruitment Flyer.
- (b) Parent(s)/guardian(s) email the primary researcher to express interest in the study.

Step 2: Initial Email Contact (Researcher-Parent/Guardian)

- (a) Primary researcher emails parent(s)/guardian(s) with information about the study.
- (b) Parent(s)/guardian(s) receive a Background Information Google Form link.
- (c) Parent(s)/guardian(s) complete the background Information Google Form.

Step 3: Background Information Collection (Researcher-Parent/Guardian)

- (a) Primary researcher reviews the completed Google Form.
- (b) Based on the Google Form responses, inclusion and exclusion criteria are assessed.
- (c) Primary researcher follows up with parent(s)/guardian(s) regarding the next steps.

Step 4A: Second Email Contact (Researcher-Parent/Guardian)

(Inclusion Criteria Not Met)

- (a) Primary researcher emails parent(s)/guardian(s) to let them know their adolescent is not eligible to participate in the study. No further action taken.

Step 4B: Second Email Contact (Researcher-Parent/Guardian)

(Inclusion Criteria Met)

- (a) Primary researcher emails parent(s)/guardian(s) to let them know their adolescent is eligible to participate in the study.
- (b) The primary researcher emails the Consent Form to the parent(s)/guardian(s).

Step 5: Ongoing Email Contact (Researcher-Parent/Guardian)

- (a) Parent(s)/guardian(s) and primary researcher arrange a virtual Google Meet meeting to review the Consent Form.

Step 6: Virtual Google Meet (Researcher-Parent/Guardian)

- (a) Consent Form is reviewed with the parent(s)/guardian(s).
- (b) Consent obtained or not obtained. If consent is not given, no further action is taken.

Step 7: Initial Email Contact (Researcher-Participant)

- (a) Participant and primary researcher arrange a virtual Google Meet meeting.

Step 8: Virtual Google Meet (Researcher-Participant)

- (a) Assent Form is reviewed with the participant.
- (b) Assent is obtained or not obtained from the participant.
- (c) If assent is obtained, participant interview is conducted immediately after. If assent is not given, no further action is taken.

Step 9: Second Email Contact (Researcher-Participant)

- (a) Participant and primary researcher arrange another virtual Google Meet meeting.

Step 10: Virtual Google Meet (Researcher-Participant)

- (a) A follow-up interview with the participant is conducted.

Appendix I

Sample Initial Email - Parents/Guardians

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Sample Initial Email Parent(s) / Guardian(s) (Template can be used for first contact)

Dear [name of parent(s) / guardian(s)],

You are receiving this email because you recently contacted me about a research study, **What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder**, that I am conducting for my Master's thesis. This study is approved by The University of Alberta Research Ethics Board (ID number Pro00105221). Thank you for expressing your interest in this study.

To determine if you want your child to participate in this research study, and to assess if your child is eligible to participate in the study, I have attached two forms (a consent form and a background information form) to this email.

Please follow these steps:

- 1) Complete the background information Google Form to ensure your child is eligible to participate in the study. This form should take around 10 minutes to complete.
- 2) After completing the Google Form, I will review it to make sure your child is eligible to participate in the study, and I will email you to tell you if they are eligible or not.
- 3) If your child is eligible to participate, please review the consent form on your own.
- 4) After you have reviewed the consent form, if you wish to proceed with giving consent for your child to participate, please email me again so we can arrange a time and day to review this form together. I expect this meeting will take no longer than 30 minutes. In your email reply please include three preferred meeting times and dates that will work for you. If you do not live in Alberta, please try to let me know what time zone you are in.

After I get your email with the meeting times and dates that work best for you, I will email you a link for Google Meets. We can use this to talk to each other online. I will also confirm the time and day we will meet. If I am not available during the times and days you originally suggested, I will provide you with some other options.

Thank you for thinking about helping with this research. Your child's input is very valuable, and I look forward to a response at your soonest convenience.

Sincerely,

Vanessa Boila, B.F.A., B.Ed., B.A. (Hons) | she/her
Graduate Student, School and Clinical Child Psychology
Department of Educational Psychology
University of Alberta

Appendix J

Sample Initial Email - Participant

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Sample Initial Email Participant

(Template can be used for first contact)

Dear [name of participant],

You are getting this email because your parent(s) / guardian(s) recently spoke with me about a research study I am doing. The study is called **What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder**, and it is approved by The University of Alberta Research Ethics Board (ID number Pro00105221).

Your parent(s) / guardian(s) think you might want to participate in this study. To help you decide, I have attached a document to this email. You can read it or look it over. You can do this by yourself or with your parent(s) / guardian(s).

After you have seen the document, if you would like to get involved, you can email me three meeting times and dates that will work for you. I expect this meeting will take about 1 hour. If you do not live in Alberta, please try to let me know what time zone you are in. If you are not sure, feel free to check with your parent(s) / guardian(s) to see if they know your time zone.

After I get your email with the meeting times and dates that work best for you, I will give you more information. I will email you a link for Google Meets, and I will email a list of interview questions, so you can look at them before we meet. We can use Google Meets to talk to each other online. I will also tell you the time and day we will meet. If I am not available during the times and days you told me, I will provide you with some other options.

Thank you for thinking about helping with this research. Your input is very valuable.

Sincerely,

Vanessa Boila, B.F.A., B.Ed., B.A. (Hons) | she/her
Graduate Student, School and Clinical Child Psychology
Department of Educational Psychology
University of Alberta

Appendix K

Sample Follow-up Email - Parent(s)/Guardian(s) - Eligible

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Sample Follow-up Email Parent(s) / Guardian(s) (Eligible to Participate) (Template can be used for follow-up contact)

Dear [name of parent(s) / guardian(s)],

You are receiving this email because you recently contacted me about a research study, **What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder**, that I am conducting for my Master's thesis. This study is approved by The University of Alberta Research Ethics Board (ID number Pro00105221). Thank you for expressing your interest in this study.

Recently, you completed a Google Form, and responded to questions about your child. I appreciate the time and effort you took to do this. I have reviewed the form, and at this time your child is eligible to participate in this study.

Here are the next steps:

- 1) I have attached the consent form. Please review the consent form on your own.
- 2) After you have reviewed the consent form, if you wish to proceed with giving consent for your child to participate, please email me again so we can arrange a time and day to review this form together. I expect this meeting will take no longer than 30 minutes. In your email reply please include three preferred meeting times and dates that will work for you. If you do not live in Alberta, please try to let me know what time zone you are in.

Thank you for thinking about helping with this research.

Sincerely,

Vanessa Boila, B.F.A., B.Ed., B.A. (Hons) | she/her
Graduate Student, School and Clinical Child Psychology
Department of Educational Psychology
University of Alberta

Appendix L

Sample Follow-up Email - Parent(s)/Guardian(s) - Ineligible

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Sample Follow-up Email (Ineligible to Participate) Parent(s) / Guardian(s) (Template can be used for follow-up contact)

Dear [name of parent(s) / guardian(s)],

You are receiving this email because you recently contacted me about a research study, **What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder**, that I am conducting for my Master's thesis. This study is approved by The University of Alberta Research Ethics Board (ID number Pro00105221). Thank you for expressing your interest in this study.

Recently, you completed a Google Form, and responded to questions about your child. I appreciate the time and effort you took to do this. I have reviewed the form, and unfortunately at this time your child is not eligible to participate in this study.

As the University of Alberta is a place of active research and innovation, there may be other opportunities for your child to participate in future research. If you are interested in learning more about forthcoming opportunities, feel free to contact the [Alberta Clinical and Community-Based Evaluation Research Team \(ACCERT\)](#) throughout the year to learn more about our upcoming projects.

Thank you for thinking about helping with this research.

Sincerely,

Vanessa Boila, B.F.A., B.Ed., B.A. (Hons) | she/her
Graduate Student, School and Clinical Child Psychology
Department of Educational Psychology
University of Alberta

Appendix M

Sample Follow-up Email - Participant

Faculty of Education
Department of Educational Psychology

Title of Study: *What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder*

Sample Follow-up Email Participant

(Template can be used for final contact)

Dear [name of participant],

You are getting this email because you recently met with me on Google Meets for a research study called **What I Want My Teachers to Know: The Lived Experiences of Adolescents with Fetal Alcohol Spectrum Disorder**, which is approved by The University of Alberta Research Ethics Board (ID number Pro00105221).

You are invited to attend an optional follow-up interview. This is a chance for you to review general information from all interviews. Your input will help ensure that the information shared by adolescents with FASD is interpreted correctly by the researcher.

If you would like to participate in this optional interview, you can email me three times and days that will work for you. The interview may take 5 to 10 minutes or it may last up to 30 minutes depending on the information you share with me. If you do not live in Alberta, please try to remind me of what time zone you are in. If you are not sure, feel free to check with your parent(s) / guardian(s) to see if they know your time zone.

After I get your email with the meeting times and dates that work best for you, I will email you a link for Google Meets. We can use Google Meets again to talk to each other online. I will also tell you the time and day we will meet. If I am not available during the times and days you told me, I will provide you with some other options.

Thank you for thinking about helping with this research. Your input is very valuable.

Sincerely,

Vanessa Boila, B.F.A., B.Ed., B.A. (Hons) | she/her
Graduate Student, School and Clinical Child Psychology
Department of Educational Psychology
University of Alberta

Appendix N

Email Template for Member Checking

Good afternoon,

I hope you're doing well. You're receiving this email because *(insert name of participant)* participated in a research study, *What I Want My Teachers to Know: The Lived Experience of Adolescents with Fetal Alcohol Spectrum Disorder*. Thank you again for sharing your experiences. I learned a lot!

As part of my research process, I've summarized the ideas youth shared with me. Now I'm hoping that *(insert name of participant)* can review the summary to make sure I have not missed any important information.

After reviewing the summary, if there is anything you feel I missed or did not get right, please let me know no later than **Friday, June 3, 2022**. If there's anything else you'd like to share with me, we can arrange a follow-up interview, or you can share your thoughts with me in an email reply. A follow-up interview is optional, which means you do not have to do it if you do not want to.

Thanks,

Vanessa

--

Vanessa Boila, B.F.A., B.Ed., B.A. (Hons) | she/her
Graduate Student, School & Clinical Child Psychology
Faculty of Education, College of Social Sciences & Humanities
University of Alberta

Appendix O

Theme Summary for Member Checking

What I want my teachers to know.		
Theme 1	Theme 2	Theme 3
<i>I am aware of ways to manage emotions and what adds to my struggles or frustrations.</i>	<i>I have preferences when I learn.</i>	<i>I value and desire meaningful relationships.</i>
<p>I also want them to know:</p> <p>1a. I want you to know what helps me relax. 1b. I want you to know what I am good at. 1c. I know some things are hard for me. 1d. I do not like some environments.</p>	<p>I also want them to know:</p> <p>2a. I enjoy learning when it is fun and interactive. 2b. I want to show you.</p>	<p>I also want them to know:</p> <p>3a. I have a hard time with some social interactions. 3b. I want to connect with others. 3c. I interact with others in my own way.</p>
<p>The youth:</p> <ul style="list-style-type: none"> ➤ Described what helps them relax. They like being with animals. Comfort items may help them feel better in class. ➤ Named what they are good at. They excel at some sports and video games. ➤ Acknowledged challenges. They can get distracted or have poor memory. They think this affects skills, like cooking, and learning activities such as those on a phone. ➤ Explained how they experience some environments affects them in good or bad ways. They do not like allergies, noise, or teachers who do not let them do things like go to the bathroom. 	<p>The youth:</p> <ul style="list-style-type: none"> ➤ Listed learning tasks they find fun. They like reading comics and graphic novels, playing games with learning in them, like making words, and they like school when teachers use games and videos. ➤ Showed the researcher objects such as toys. They shared their screen to tell what they like to do on a phone or computer. They liked to show <i>and</i> tell. 	<p>The youth:</p> <ul style="list-style-type: none"> ➤ Shared that bullying is an issue, and said they have few friends at school. Sometimes they do not want to tell teachers about how bullying affects them. They think when teachers know about it, they do not help. ➤ Expressed they want know about others. They wanted to learn about the researcher, so they asked her questions. They said they may be friends with a bully if they were nicer. They also said the pandemic has affected their friendships. ➤ Interacted in ways unique to them. They sometimes replied with phrases they know and like. They moved around a lot, had pets nearby, or asked for the meaning of a word or for a question repeated.