Self-Determination in Children with Fetal Alcohol Spectrum Disorder:
A Bioecological Perspective

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August 2018

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of

Doctor of Philosophy in School/Applied Child Psychology

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Abstract

The current study explored self-determination (SD) in children diagnosed with Fetal Alcohol Spectrum Disorder (FASD). This population has rarely had their voices heard in matters relating to their education, and never regarding SD. Using a bioecological approach, the children's individual characteristics and environments were investigated through multiple perspectives and sources. Eight children aged 10-15 took photographs of what they felt most successful at and what they identified as most challenging at school. They participated in a brief semi-structured interview, and completed questionnaires regarding their SD and quality of life (QoL).

Their teachers and guardians also completed questionnaires assessing adaptive behavior, SD, and QoL. Using a descriptive phenomenological qualitative approach, data were analyzed through thematic analysis. While the proxies and the children's responses appeared to be context-dependent, most participants agreed on the following regarding the children: they struggle with academics, they are socially oriented but have difficulty socializing, they have reduced executive functioning. Further, adults appear to assume the children need support, and there is a risk of over-estimating the pathology of the children's behaviors. Several individual and environmental characteristics appeared to interact to influence the children's SD. Namely, difficulties in executive functioning may have a cascading negative effect on several other areas of functioning, leading to decreased SD. Those involved in research, policy, or practice in the field of FASD are provided with suggestions for future directions such as use of visual data in understanding children's perspectives, having cognizance of contextual factors that may influence development, and fostering SD.

Résumé

La présente étude a exploré l'autodétermination (AD) chez les enfants ayant reçu un diagnostic de trouble du spectre de l'alcoolisation fœtale (TCAF). Cette population a rarement fait entendre sa voix en matière d'éducation, et jamais en matière de AD. En utilisant une approche bioécologique, les caractéristiques individuelles et les environnements des enfants ont été étudiés à travers de multiples perspectives et sources. Huit enfants âgés de 10 à 15 ans ont pris des photos de ce qu'ils considéraient comme le plus réussi et ce qu'ils considéraient comme le plus difficile à l'école, ont participé à une brève entrevue semi-structurée et rempli des questionnaires sur leur AD et leur qualité de vie. Leurs enseignants et tuteurs ont également rempli des questionnaires évaluant le comportement adaptatif, l'AD et la qualité de vie. À l'aide d'une approche qualitative phénoménologique descriptive, les données ont été analysées par analyse thématique. Alors que les réponses des enfants et les réponses des enfants semblaient être dépendantes du contexte, la plupart des participants étaient d'accord sur ce qui suit concernant les enfants: ils ont de la difficulté avec les études, ils sont orientés socialement mais ont de la difficulté à socialiser; ils ont réduit le fonctionnement exécutif. Aussi, les adultes supposent que les enfants ont besoin de soutien, et il y a un risque de surestimation de la pathologie des comportements des enfants. Plusieurs caractéristiques individuelles et environnementales semblent interagir pour influencer de l'AD des enfants. À savoir, les difficultés dans le fonctionnement de l'exécutif peuvent avoir un effet négatif en cascade sur plusieurs autres domaines de fonctionnement, conduisant à une diminution du AD. Les personnes impliquées dans la recherche, la politique ou la pratique dans le domaine de TCAF reçoivent des suggestions d'orientations futures telles que l'utilisation de données visuelles pour

comprendre les perspectives des enfants, la connaissance des facteurs contextuels pouvant influencer le développement et favoriser l'AD.

Acknowledgements

Thank you to the children and parents who participated in my study. I remain touched by their stories and am impassioned to help create a more inclusive, safe, and empowering school experience for children with FASD. I carry my experiences with these families with me in my clinical work, ensuring that children with a disability are treated with respect and are provided with the support they need to succeed. Thank you also to the school administrators and teachers who allowed me into the schools and to take up some of their already limited time.

To Dr. Tara Flanagan, my research supervisor, thank you so much for your insights, ideas, and seemingly unwavering patience and support. I truly appreciate the time and effort you gave to help me feel confident in this endeavor. Thank you to the team of brilliant professors that aided in various stages of research and data analysis along the way: Dr. Claudia Mitchell, Dr. Armanto Bertone, and Dr. Jessica Ruglis. I am also greatly appreciative of the Fonds de Recherche de Québec--Société et Culture (FRQSC) for funding my research.

Thank you to my father, Kelly Dupasquier, who not only instilled in me the work ethic necessary to earn a Ph.D., but also encouraged me to study FASD. Thank you to my aunt, Madeleine Bazin, whose support and generosity made completing this work possible. Also, a huge thanks to my aunt, Francine Desroches, who edited my French translation of my abstract.

To my wonderful friends and editors, Dr. Hailey Sobel, Dr. Petra Gyles, Jennifer Dyck-Sprout, I owe thanks to helping me remember what is important both on and off the pages of this dissertation. I thank my partner, Darryl Block, for his consistently intelligent and thoughtful comments on my work, and for his gracious support throughout the writing process.

This work is dedicated to my late mother, Simone Dupasquier, who taught me perseverance and to challenge our assumptions.

Self-Determination in Children with FASD: A Bioecological Approach

By the time children with fetal alcohol spectrum disorder (FASD) reach high school, they have likely experienced a lifetime's worth of personal and systemic disregard. FASD is one of the few remaining disorders with which a heavy burden of open judgment and stigma is attached. The word stigma is, "used to refer to an attribute that is deeply discrediting" (Goffman, 1963, p. 3), and in practice, " …we believe the person with a stigma is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances" (Goffman, 1963, p. 5). Perhaps in part due to the societal decree of "less than" associated with FASD, schools, education boards, and arguably the Canadian government, often neglect the needs of this notoriously underserved population (Bredberg, 2011; Duquette & Orders, 2010; Tait, 2000). As such, families and children impacted by the disorder often must advocate for themselves to receive educational services (Duquette, Stodel, Fullarton, & Hagglund, 2012), often facing a barrier of ignorance at all levels of educational policy (Duquette & Orders, 2010).

Self-determination (SD) skills are frequently referenced by disability studies scholars as vital for the educational services received by children with disabilities (Lee, Wehmeyer, Palmer, Soukup, & Little, 2008; Wehmeyer et al., 2007). Self-determined behavior is defined in disability studies as, "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 117), of which goal-setting and behaviors related to meeting goals is a crucial component (Wehmeyer, Sands, Doll, & Palmer, 1997). School is the most salient institution in children's lives, and it is where children with disabilities learn and practice many of their SD skills (Hughes, Cosgriff, Agran, &

Washington, 2013), skills imperative to positive adult outcomes (Heller et al., 2011; Shogren, 2015; Wehmeyer & Palmer, 2003).

While many disability groups are well represented in SD literature (Chou, Wehmeyer, Palmer, & Lee, 2017; Parker & Boutelle, 2009), SD has yet to be studied in children diagnosed with FASD. In today's educational system, children with FASD may not have full access to the resources required to succeed socially and academically (Bredberg, 2011). The barriers impeding their access to quality education may be subtle and multi-dimensional in nature, and thus require investigation from several perspectives and from a variety of methods. Bronfenbrenner (1979, 1994, 1999; Bronfenbrenner & Morris, 2006) theorized a bioecological model in which human development occurs within a context of increasingly complex and reciprocal interactions between biopsychosocial humans and the objects, people, and symbols in their environments. This model is used in the current study to conceptualize the understanding of the participants' experiences. Overall, this study seeks to explore the factors that may influence the SD of children diagnosed with FASD.

The ideal research approach to investigate such a multidimensional issue is qualitative. Such studies are used to understand complex, multi-faceted phenomena through the perspective of the study's participants (Creswell, 2014), which is particularly important given that in general, children's voices are often unheard in matters relating to their education (Cavendish, 2013; Hughes et al., 2013). The perspectives of the children in the present study are core to understanding their capacities and opportunities for SD at home and school; their perceptions of their abilities and environments provide detail and insight unavailable through surveying their guardians and teachers. Several qualitative studies focused on adults and children with FASD (Duquette & Stodel, 2005; Duquette, Stodel, Fullarton, & Hagglund, 2006a; Knorr & McIntyre,

2016) have provided key insights into how people with FASD feel regarding their school experiences. However, to date no study has investigated this population's experience from a bioecological viewpoint, and none have explored the SD of people with FASD.

To address SD in children with FASD specifically, the disability-focused interpretation of SD theory presented by Wehmeyer (1992; 1998; 2005) was the best fit as a guide in the development of the current research. His interpretation provided a framework for actionable interpretations and concepts from SD theory such as decision-making, goal-setting, and autonomous completion of tasks. This interpretation encourages helping people with a disability only when required to allow for the development of SD, even in cases where the person requires a considerable amount of support. Increasing the autonomy of people with a disability encourages reliance upon their own adaptive behavior, the development of which has a strong relationship with SD (Perry & Felce, 2005; Stancliffe, Abery, & Smith, 2000).

The American Association for Intellectual and Developmental Disabilities (AAIDD) describes adaptive behavior as the confluence of practical, social, and conceptual skills (FAQ on AAIDD, 2017), where certain skills, behaviors, and abilities are required for a person to function independently in activities of daily life. People with FASD often struggle significantly with adaptive behavior (Edwards & Greenspan, 2010), and the construct has yet to be explored in children with FASD within a bioecological framework. This overlooked area can provide a host of information regarding personal characteristics of children with FASD that can be used to better understand their SD.

Among people with disabilities, increased SD results in increased positive outcomes (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Schalock, 2001). Schalock, Verdugo, Gomez, and Reinders (2016) describe positive outcomes within the framework of quality of life

(QoL). Specifically, QoL is defined through a set of eight principles, namely (a) physical well-being, (b) emotional well-being, (c) material well-being, (d) interpersonal relationships, (e) personal development, (f) social inclusion, (g) rights, and (h) self-determination (Schalock et al., 2016). Additionally, the principles reach across the different strata of development, including intra- and interpersonal interactions and broader environmental influences, consistent with Bronfenbrenner's bioecological model (1999; Bronfenbrenner & Morris, 2006).

The current study considered SD and adaptive behavior in the home and school environments, as well as child participants' own perceived and observed QoL at home. The participants will be referred to as children, children with FASD, or students, unless otherwise specified. There were several sources of data, including photographs, interview, and questionnaire data. The use of multiple methods of data elicitation has been shown to be effective in previous studies with children (Darbyshire, MacDougall, & Schiller, 2005; Duquette & Stodel, 2005; Obrusnikova & Cavalier, 2011). Specifically, to draw out the children's perspectives on their SD at school, they were asked to record through photography what they felt most successful at and what they found the most challenging at school. Taking the photographs provided a chosen artifact through which to discuss aspects of their school life, affording insight into the choices they make at school and what might motivate these choices. Photographs taken by the children are quintessential qualitative representations of their experience within the educational environment (Mitchell, 2008). By giving each child a means to capture images of what they feel the most successful at and what they find the most challenging at school, any written or spoken language barriers are greatly reduced, and the child's viewpoint rises to the forefront.

Their photographic responses were supplemented by a brief semi-structured interview regarding their images. Questionnaire data concerning their QoL and SD, completed by the child as well as by a guardian and teacher were also acquired. Open-ended questions from the SD measure elicited information regarding the children's goals and their progress toward meeting those goals. A standardized measure of their adaptive behavior skills as seen at home and at school was also obtained. The data from all questionnaires were analyzed qualitatively from within the bioecological framework (Bronfenbrenner, 1999; Bronfenbrenner & Morris, 2006). With the participants aged between 10 and 15, the tasks were developmentally appropriate and engaging.

The purpose of the current study was to explore the SD of children with FASD by investigating how children's self-perceived successes and challenges at school are reflected and understood in how they, their guardian, and their main teacher perceived their level of SD. Their goals and progress toward meeting their goals provided additional information regarding their SD from their own and their proxies' perspectives. Of further interest was how their abilities at home and school, as assessed by a standardized measure of adaptive behavior, further informs understanding of the children's SD and what the children chose to photograph. Finally, given that QoL is inextricably linked to SD (Nota et al., 2007; Wehmeyer & Schalock, 2001), the children's QoL was measured from the child and guardian viewpoints to explore how the results may be reflected in the other sources of data.

The dissertation is organized in the following manner. The literature review will include extensive discussion and critical analysis of research relating to the population of interest (students with FASD), the bioecological model, SD, and QoL. Gaps in knowledge will be identified and the research questions will be presented. The methodology section will include a discussion of descriptive phenomenology and why it was chosen as the qualitative method research paradigm. It will also entail descriptions of the instruments used in the study, as well as a presentation of photograph-taking and brief semi-structured discussion of the photographs as important sources of data. The methods section will further include an overview of the data analysis, validity procedures, and ethical considerations. The findings of the study will be presented in the results section. The final section, the discussion, will include further analysis of the findings, limitations of the study, and the translation of major findings into practical implications for research, policy, and practice.

Literature Review

Fetal Alcohol Spectrum Disorder

FASD is the leading known cause of preventable developmental and intellectual disability in the world (Tough, Tofflemire, Clarke, & Newburn-Cook, 2006). After children with this diagnosis graduate from high school, they are at-risk for confinement (in mental health institutions or because of involvement with the criminal justice system) in Canada and elsewhere (Burd, Klug, Li, Kerbeshian, & Martsolf, 2010; Streissguth, Barr, Kogan, & Bookstein, 1996).

The widely variable manifestations of the disorder require complex approaches to diagnosis, research, and educational policy and practice (Bredberg, 2011; Duquette & Orders, 2010; Duquette & Stodel, 2005). The guidelines for diagnosis and the available knowledge on prevalence and the risk factors associated with the development of FASD are addressed below. The complexities surrounding these concepts are explored in relation to historical and current political contexts.

Diagnosis, prevalence, & risk factors. The specific effects of alcohol on the fetus are numerous and varied, resulting in a complex process not only for diagnosis but also for determination of prevalence rates. As will become apparent, the risk factors relating to mothers drinking alcohol while pregnant are vital to the understanding of these complexities and to responsibly design research in the field of FASD.

Diagnosis. The disorder was first described as a medical condition just over a generation ago (Jones & Smith, 1973, 1975; Lemoine, Harousseau, Borteyru, & Menuet, 1968). At the time, the diagnosis was based solely on the presence of physical characteristics common in infants heavily exposed to alcohol in the womb such as thick epicanthic folds, small palpebral fissures, smooth philtrum, flat mid-face, and thin upper lip. Since then, the nomenclature of the disorder has expanded and evolved to include behavioral, motor, and cognitive symptoms, and has included diagnoses for the neurological symptoms present without physical symptoms (Chudley et al., 2005).

According to Riley, Infante, and Warren (2011), there are four major classification systems in use in North America to guide the diagnosis of FASD; the University of Washington’s 4-Digit Code system, the Revised Institute of Medicine (IOM) guideline, the National Task Force/Center for Disease Control (CDC), and the Canadian Guidelines that harmonize the differences between the 4-Digit Code system and the IOM’s guideline. The current study will focus on the Canadian guidelines.

The Canadian guidelines stipulate that FASD is a diagnostic term that describes the impact alcohol can have on the developing fetus (Cook et al., 2015). For the remainder of the dissertation, the acronym FASD will refer to all previous nomenclatures such as fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol related neurological deficits (ARND) prenatal alcohol effects (PAE) unless otherwise specified.

FASD symptoms include presence of facial abnormalities (short palpebral fissures, thin upper lip, and smooth philtrum), cognitive difficulties such as poor memory, attention, abstract reasoning and executive functioning, as well as difficulties in receptive and expressive language (Cook et al., 2015). Academic achievement is typically lower than would be expected for the individual's age, especially in the areas of mathematics and written expression. Social skills and social communication are often negatively impacted wherein the individual has difficulty judging character and understanding if they are being manipulated. They may also have a limited grasp of boundaries, quickly becoming too personal with others in physical or emotional realms. Quite often they display hyperactive and impulsive behaviors. Individuals with FASD can struggle with transitions and adapting to change. Specific brain structure anomalies are seen, including a reduced or almost absent corpus callosum or cerebellar hypoplasia causing poor hand-eye coordination and poor balance that may present as an imbalanced tandem gait. Evidence of slowed growth from birth is necessary for diagnosis. Confirmed exposure to alcohol in the womb is recommended but not required if the child exhibits facial abnormalities; without these facial abnormalities, alcohol consumption during pregnancy must be confirmed.

To exacerbate these issues, there is evidence to suggest that exposure to alcohol in utero can affect the stress system in the developing brain, resulting in the individual's stress system reacting hyper-sensitively to stressful events in their lifetime and thus increasing their likelihood of developing mood and substance-use disorders in adolescence and into adulthood (Uban et al., 2011). Encouragingly, early diagnosis and intervention can mitigate these effects (Kalberg & Buckley, 2006; O'Leary, 2004).

Prevalence. In the context of this study, prevalence refers to the number of people diagnosed with FASD at a specific point of time within a specific region. A recent meta-analytic study on the global prevalence of FASD found it to be at 7.7 per 1000 births with 76 countries reporting higher rates of over 1% (Lange et al., 2018). In Canada, the prevalence is reported to range from approximately 2% to 3% (Popova, Lange, Chudley, Reynolds, & Rehm, 2018).

In comparison, the United States prevalence rate is estimated to be similar to Canada's ranging from 1% to 5% (May et al., 2018) while in Australia, prevalence is lower at approximately 0.02/1000 in non-Indigenous populations and 2.26/1000 in Indigenous communities (O'Leary, 2004). France is reported to have approximately 4.8/1000 cases of FASD born in each year, while in the Western Cape province in South Africa, the rate is much higher at 39.2/1000 (May et al., 2000). The findings suggest culture may impact prevalence rates. A closer examination of the procedures in prevalence research and reporting is required.

Researching and reporting prevalence. Determining the prevalence of FASD in Canada is a complex undertaking. There is a high risk of under-reporting prenatal alcohol exposure due to fear of stigma and judgment. For the same reason, some families may not seek a diagnosis. Diagnosis can be challenging for several reasons. The Canadian guidelines stipulate that a multidisciplinary team is required to make a formal diagnosis. Those included on the team would include a physician with specialized knowledge of FASD, a psychologist, a case manager such as social worker or nurse, an occupational therapist, and a speech-language pathologist (Chudley et al., 2005; Cook et al., 2015). These professionals have a high level of expertise, and due to location or lack of funding, certain communities may not have access to their services. Therefore, there is a high risk that the prevalence rates are an underestimate.

These conditions make research difficult. When research is successfully conducted, differing methodology and terminology between studies makes meta-analysis difficult if not impossible. There is also a political aspect that may skew findings toward marginalized communities. Tait (2000) argues that Indigenous reservations have been targeted for FASD research outwardly due to these regions being at high-risk for FASD incidence, but also and perhaps equally because of the communities' characteristics: high level of current and past information available due to low migration in and out of reserves, uniform population, and the close monitoring of pregnancies due to the necessity of transportation to hospitals in other communities.

Risk factors. Unfortunately, for a certain number of cases of FASD, some facets of the stereotypes are the reality. In Manitoba in 2004, for example, children with FASD were highly over-represented in the number of children in foster care; specifically, 11% of children in care had FASD (Fuchs, Burnside, Marchenski, & Mudry, 2007). Further, of the children in care identified as having a disability, a third had FASD (Fuchs et al., 2007). These statistics suggest that a child with FASD is likely to have an unstable family background or likely to grow up in an area without access to the services and resources required to prevent FASD. A closer look at the research, however, reveals findings that refute these stereotypes.

For example, an American five-year follow-up study of mothers who gave birth to children with FASD resulted in a subject pool with similar demographics to what was a nationally representative sample at the time of the study--in other words, they were from diverse educational, economic and ethnic backgrounds, with no predisposing factors based on these characteristics alone (Astley, Bailey, Talbot, & Clarren, 2000). In Canada, Chudley and colleagues (2005) posited that a higher maternal age, paternal drinking and drug use, and inadequate access to pre- and postnatal services were greater risk factors than ethnicity and education. In fact, Tough and Jack (2011) found in their review of Canadian prevalence rates of FASD that biological mothers were likely be Caucasian and to have a high income.

Furthermore, surveys in Alberta have shown that approximately *half* of all first-time mothers drank alcohol during their pregnancy before they knew they were pregnant (Tough & Jack, 2011). Additionally, 11% of Canadian mothers admitted that they consumed some alcohol during their pregnancy (Public Health Agency of Canada, 2008) and 14% of American women reported that they drank while pregnant (Nixon, Prather, & Gilbertson, 2011). However, according to another American study, the estimate is much higher at 40% consuming alcohol during pregnancy, with 3-5% of women reporting heavy drinking during pregnancy (Floyd & Sidhu, 2004). With drinking rates this relatively widespread, race and economic status alone cannot account for rates of maternal drinking.

Overall, the greatest risk factor related to having a child with FASD is blood-alcohol-concentration: the frequency with which the mother drinks, how much is consumed at a time, and at what point in the pregnancy she drinks are all important variables (Chudley et al., 2005). While there is no known threshold amount of alcohol that causes FASD, the effects appear connected to dose (Chudley et al., 2005), and not race, environment, or socio-economic status. However, it is possible that the treatment of the disorder can be negatively impacted by such factors. The political and historical context surrounding the development of FASD as a disorder is required to obtain a deeper understanding of the factors related to its prevention and treatment.

Political history and its current implications. There exists a long history of stigma toward families impacted by FASD that has influenced policy, practice, and research into the disorder (e.g., Armstrong & Abel, 2000; Hunting & Browne, 2012). Thus, it is important to understand the circumstances from which the stigma arose.

As an immoral indiscretion. Following the instability of the 1960's, there was a renewal of conservative politics, and with it, an increase in ideology associated with personal responsibility and self-restraint (Armstrong & Abel, 2000). It was during this era that FASD became a greater focus of public awareness and a larger area of interest in research studies. The tone of discussion about the disorder was negative, with the disorder being labeled as “tragic” by the researchers often credited for its discovery (Jones & Smith, 1975). Abortion was recommended for alcoholic pregnant mothers up until the 1980’s (Armstrong & Abel, 2000). By the 1980’s, discussions around the topic of alcoholism were rampant in North American culture, as shown by the burgeoning of associations such as Mothers Against Drunk Driving (MADD), lowered blood alcohol level allowances for driving, and increased legal drinking ages (Armstrong & Abel, 2000). These discussions often imply and ascribe a lack of morality, control, or disease to someone who drinks.

Regrettably, the issue in Canada denotes further marginalization by way of the link to race. Canada (i.e., its people, government, research community) tends to view FASD as an Indigenous issue (Hunting & Browne, 2012; Tait, 2000), despite knowledge that other ethnic groups drink while pregnant (Tough & Jack, 2011). Hunting and Browne (2012) discuss how much of research, policy, and media does not examine the reasons underlying why a woman may drink while she is pregnant. For example, a widening health care gap exists between northern communities and the rest of Canada that impacts on the level of prenatal care she may receive. Further, there is longstanding evidence that healthcare provision and policy is often racialized and individualistic, ignoring the social and structural barriers many women face in their pursuit of health (Hunting & Browne, 2012). In this setting, Indigenous women are portrayed as perpetrators toward the cause of FASD, and the conditions that lead to their alcohol use are ignored. The women are thus stigmatized and services are limited due to this perception that they brought the disease unto a helpless child, perhaps knowingly.

Further, there is a strong implied notion in Canadian policy that there is a lack of prenatal education in reserve communities, and that Indigenous women must then be put under surveillance or otherwise not trusted to take care of their unborn child unaided (Hunting & Browne, 2012; Tait, 2000). This increases the stigmatization of Indigenous mothers and decreases attention toward the contextual factors leading to alcohol use. Additionally, prevention strategies are often abstinence-based, individualistic and therefore judgmental.

While it would be naïve to claim that reports of higher incidence rates of FASD in northern communities are based solely on prejudice, the issues of contexts, environments, and conflicting evidence regarding this assumption are rarely discussed in any of the literature save for those authored by people amid (founded) political outrage such as Tait (2000) and Hunting and Browne (2012). Current research on the topic tends to focus primarily on individual characteristics (e.g., Kodituwakku, 2009). Additionally, others often treat those with a diagnosis of FASD with some level of fear, reticence, or general negative attribution bias (Bell et al., 2016). To ignore prejudice in the lives of developing children with FASD is to ignore vast swaths of experience, or lack of experience, this population encounters.

Impact of prejudice. "Research shows that the incidence of fetal alcohol spectrum disorder is considerably higher among Indigenous peoples and in rural, remote and northern communities" (Gravelle, 2014). This quote is from Mr. Gravelle, a member of the Canadian parliament, and is included in the Hansard records of parliamentary debate. No other members of parliament refuted his words publicly, despite the fact they are debatable (Astley et al., 2000; May et al., 2009; Tough & Jack, 2011). This statement speaks loudly to the assumptions the decision-makers of the Canadian government make about FASD and exemplifies the potential stereotypes people impacted by the disorder battle daily.

Furthermore, mental health issues are generally highly stigmatized and, in part due to this stigma, those impacted avoid seeking and/or maintaining services (Clement et al., 2015). The stigma and presumption associated with a diagnosis of FASD can deter families from seeking services, create familial grief, guilt, shame, and conflict, and cause negative bias in social and academic settings throughout an individual's lifespan. Protective factors such as support groups and self-advocacy commonly available to people who have other disabilities are not nearly as abundant or developed. Self-advocacy within the FASD community is virtually non-existent; online searches by the current researcher for advocacy groups in North America reveal not only a shortage of services but also a lack of membership in these groups.

Further complicating the issue, the majority of FASD cases present as "invisible disorders" with no or few physical characteristics and low average to high average intelligence (Duquette & Orders, 2010). It is easy for some to "hide" their disorder under a veneer of another, less stigmatized issue such as attention deficit/hyperactivity disorder (AD/HD), further ostracizing those with more severe symptoms.

The effects of prejudice seep into all aspects of a child's life. Presently, education policy and practice does not always account for the complex implications of a FASD diagnosis (Ryan & Ferguson, 2006). In Ontario school boards, FASD is not an eligible disability classification for special services (Duquette & Orders, 2010). Thus, children with FASD who have co-morbid disorders such as ADHD, emotional disturbance, autism spectrum disorder (ASD), or learning disability (LD) may receive services targeted toward their co-morbid disorder rather than for FASD. Frequently, children with FASD receive services based on their behavioral phenotype (Bredberg, 2011). These factors prevent seeing the challenges the child is having at school as a potentially pervasive issue with an underlying etiology, and compartmentalizes their experience.

Additionally, many teachers and educators simply do not know much about FASD (Bredberg, 2011), the reasons for which may lie in a lack of opportunity to learn about the disorder. In Bredberg's (2011) review of the literature surrounding educational policy, she found that no teacher education specifically addressed FASD in North America. Further, only one half-page to five pages of the textbooks assigned in teacher preservice education were typically devoted to FASD. The lack of educator training and knowledge of the disorder can only have detrimental results. Indeed, the point is made clear in the following account of an adult with FASD recalling his experience at school:

> I do have some good memories of junior high school: I remember being one of the top athletes in the school; I enjoyed making my teachers and classmates laugh; and I did really well in drama. I totally understand that it is not easy being a teacher–one teacher to thirty-plus students is unbelievable. I do wish though, that more training on FASD was given in the university for teachers. I feel that if my teachers had known more than they had about FASD, they may have been able to understand, and perhaps could have offered me better support. (Himmelreich, 2011, p. 414)

Summary of FASD. FASD is a complex disorder in terms of diagnosis, research, treatment, presentation of symptoms, and educational support and policy. Furthermore, its political and historical roots are mired with prejudice, thus compounding the complexity. Children with FASD are often faced with a tremendous amount of stigma originating from a lack of understanding of the disorder, a lack of empathy toward its causes, and misaligned or lacking school policies.

Bioecological Model of Human Development

Environmental and individual factors inhibit access to quality education and therefore requires investigation from several perspectives. Thus, a bioecological view of development at home and school is helpful to better understand the SD of children with FASD. As such, the over-arching framework of the present study is based on Bronfenbrenner's (1999; Bronfenbrenner & Morris, 2006) bioecological model of human development. Bronfenbrenner (1999; Bronfenbrenner & Morris, 2006) believed that human development occurs within a context of increasingly complex and reciprocal interactions between a biopsychosocial human and the objects, people, and symbols in its environment. The model itself is complex, multi-dimensional, and attempts to encompass all aspects that impact on a child's development. Development must occur through *process*, a concept explained shortly.

The model can be visualized as three concentric rings (Bronfenbrenner 1994, 1999). The microsystem: a person's biology, personality characteristics and their relationships with "structures" within the immediate environment (e.g., objects, people, symbols that the person engages with directly) such as family. The mesosystem: interactions between the elements within the microsystem (e.g., connection between the child's neighborhood and parents). The macrosystem: the outermost circle, is the most abstract concept of the model. The macrosystem represents the values and beliefs the child accumulates through their development. It is the lens through which they interpret life events. The child's culture, country's government, socio-economic status, as well as the interactions between the microsystem and mesosystem emcompass the macrosystem; these factors influence both what and how the child experiences.

In addition to the three concentric rings, there exists an exosystem representing factors that indirectly influence the developing individual but do not contain the individual themselves

(Bronfenbrenner 1994; 1999). The factors within the exosystem must exist within the direct proximity of the person for the factors to be considered part of the model. For example, a child's parents' health insurance would impact the child's access to auxiliary services such as dental check-ups, occupational or physical therapy, or psychological counselling.

The model also includes the choronosystem; it represents time as it pertains to the child's environments (Bronfenbrenner 1994; 1999). Examples include the timing of a child's parent's death as compared to same-aged peers, or when they begin puberty. Historical context also falls under this system (e.g., Great Depression, unstable political leadership, population boom due to immigration), as does the individual's family's reactions or role transitions in such contexts.

The *process* of development within the bioecological model is an important concept in research and practical applications. Bronfenbrenner (1994, 1999) and Bronfenbrenner and Morris (2006) stated that for development to occur, the individual must engage in an activity on a regular basis with little interruption. The activity must increase in complexity as the child masters a skill or concept. The process of development is not unidirectional, and can involve interpersonal interaction, objects, and symbols. As such, development does not occur in a vacuum; thus, controlling for such variables as social class, ethnicity, and household composition in hopes of isolating a "pure" process produces incomplete information. Rather, each of these factors are important to consider within the context in which the process is occurring.

The bioecological theory is popular in disability studies research, and is beginning to be integrated into policy. For example, Walker et al. (2011) used a social-ecological approach in their government-funded presentation of an intervention model promoting SD in people with intellectual and developmental disabilities in the United States. They included five levels for targeted intervention based on the premise that personal characteristics interact with and influence the person's environment. Briefly, the intervention model emphasized identifying: (a) the person-specific and ecological-specific variables related to SD that are relevant to the individual, (b) intervention practices informed by those variables, (c) mediating variables, (d) interventions targeted at promoting the mediating variables, and (e) outcomes that not only show an increase in SD but also help to proliferate positive impacts of the interventions. As a rough example, an outcome of greater community involvement would lead to increased social inclusion, which increases opportunities to practice SD, leading to greater motivation within the individual to further their capacity to gain and practice SD skills.

Wehmeyer et al. (2011) investigated moderating variables across different levels of a person with a disability's life including micro-, meso-, and macrolevel influences on the development of SD. The researchers posited that a person's decisions about the contexts in which they interact with others, live, learn, and behave have direct influence on their potential to gain further SD, or have SD reduced. Moderating variables on these influences included culture (e.g., individualistic versus collectivistic communities, parenting style), gender, age and stage of life, cognitive ability, affiliation with or belief in religion/spirituality, and experiences of discrimination/segregation/oppression, showing that there are multiple influences on a person's SD development.

The bioecological model has been adopted in newer theoretical definitions of intellectual disability. Specifically, Buntinx and Schalock (2010) had theorized that having an intellectual disability is assumed by the public to impact on the level of community participation the person engages in, the person's health, and the societal roles the person plays. However, assessment for intellectual disability is commonly focused only on the person's level of intelligence and their adaptive skills, not necessarily on the full scope of what the person is capable of or on the person's health and well-being. A more thorough assessment would then necessitate an expansion to include the person's health, community participation, and role in society. Hence, the authors recommend a multi-dimensional approach to fully comprehend intellectual disability. Indeed, the World Health Organization's definition of disability includes these considerations (WHO, 2007).

The Process-Person-Context-Time (PPCT) model (Bronfenbrenner & Morris, 2006) highlights that the proximal processes between the developing individual and their environment are integral to their development, and that these interactions can influence progressions and regressions. In earlier versions of Bronfenbrenner's model (1994; 1999), the person was viewed as at the center of environmental influence; the person was portrayed as a passive bystander. The PPCT model instead allows for the acknowledgement that a person's characteristics can significantly influence their environment. Characteristics may include age, gender, race, motivation, emotional and mental resources, or past experiences. These individual characteristics can set off a feedback loop where the proximal processes influencing a person's development are impacted by their characteristics. Bronfenbrenner and Morris (2006) highlighted that even when provided with equivalent access to material resources, children develop differently given their personal characteristics. Overall, within the PPCT model, a person's individual influence on their own development is given a major role.

Context within the PPCT model refers to the micro-, meso-, exo-, macro- and chronosystem influences on development discussed earlier in the description of the bioecological model. These factors are still thought to comprise an integral role in an individual's development, but the processes and personal characteristics are given more weight in the more modern PPCT model.

The final aspect of the PPCT model is time, where time considerations expand beyond the influences of the chronosystem to the additional reflection on what is happening in the individual's environment at the time that the proximal process is occurring, and how frequently the individual is engaged in the process.

The most modern iteration of the bioecological model highlights the importance of using the PPCT model when conducting research (Bronfenbrenner & Morris, 2006). In the PPCT model, the processes between the individual (including their personal characteristics such as adaptive behavior or psychological tendencies) and their environment over time are paramount over a focus on the environment and contextual influence on an individual's development, as was the case in earlier versions of the model (e.g., Bronfenbrenner, 1979).

Summary. Individual and environmental characteristics can impact the SD of a child with FASD. The foundational work by Bronfenbrenner (1994; 1999) outlined the influence of environment on understanding development through use of a bioecological model. The PPCT model (Bronfenbrenner & Morris, 2006), is a modern iteration of this work and places greater weight on the proximal processes between the individual and their environment, as well as on the person's individual characteristics that may influence these processes. Within the PPCT model, this study explores the SD of the children participants from multiple vantage points. While SD has been discussed within the PPCT model, the concept itself has yet to be fully explored. A discussion describing SD, how it lends itself to interpretation within the PPCT framework, why it is especially important for those with FASD, and research regarding the environmental and individual characteristics that influence SD follows.

Self-Determination

It has been established that children with FASD have difficulties that require support for the wide-ranging difficulties they can present with at school. People who require support because of their disabilities have the right to behave in self-determined ways; however, children with FASD often encounter difficulties in the school regarding obtaining support (Duquette & Orders, 2010), and it is unknown if their SD is being considered when supports are being developed for them. A comprehensive understanding of SD as a concept is required so that areas where children with FASD can learn and practice their SD skills at home and school can be identified.

Characteristics of SD. The construct of SD was thoroughly examined by Wehmeyer, Abery, Mithaug, and Stancliffe (2003). In their text, three theoretical underpinnings of SD were brought forward: an ecological model of SD, a model of SD that is focused on self-regulation, and a functional model of SD. The overarching connection across the three models was that SD was situated within the construct of human agency as explained by Bandura (2001) wherein individuals choose and cause action to occur with intention and purpose. Therefore, a person's behavior is volitional and the behavior has a causal impact on their environment. The functional model of SD is typically what is most amenable to research applications, and as such has been used in several studies involving individuals with disabilities. Thus, the functional model of SD is of focus in the following section. For a more fulsome review of SD focused on self-regulation and of the ecological model of SD, the reader is encouraged to refer to Wehmeyer et al. (2003).

The functional model of SD has been empirically validated for use in assessment and intervention planning across different cultural contexts (Wehmeyer et al., 2011). Behaviors associated with SD emerge in childhood (Heller et al., 2011) and develop according to personal attributes and environmental characteristics such as an inclusive versus segregated school setting

(Lee et al., 2008; Shogren, Wehmeyer, Palmer, & Paek, 2013) or the opportunity for practice (Carter, Lane, Pierson, & Glaeser, 2006), and culture (Shogren, 2011). First outlined by Wehmeyer et al. (1997), conduct that is considered self-determined is characterized by the following four elements: "(1) the person acts autonomously, (2) the behavior is self-regulated, (3) the person initiates and responds to the event(s) in a psychologically empowered manner, and (4) the person acts in a self-realizing manner" (Wehmeyer et al., 2011, p. 21), in that self-realizing actions are those that benefit the individual and help them to achieve valued goals. The essential characteristics of SD develop over time. Self-determined actions require such skills as choice making, goal setting, self-regulation, self-advocacy, self-awareness, and problem solving.

To elaborate on the first of the four essential characteristics of SD, a person behaves autonomously when the actions that they perform are within their interests, ability level, or preferences (Wehmeyer et al., 1997). Additionally, the actions they undertake are not unduly interfered with or influenced by another person. For example, activities related to taking care of one's self and family, interacting with the environment, engaging in recreation, and participating in social and vocational endeavors are characteristic of autonomous behaviors.

Self-regulated behaviors relate to self-awareness of how one is managing in a situation (Wehmeyer et al., 1997). To be successfully self-regulated, a person must monitor and evaluate themselves and their circumstances, and adjust accordingly. To do so, goal setting is important, as is engaging in self-instruction and/or self-reinforcement.

The concept of psychological empowerment refers to when a person feels as though they have control over the circumstances of their life (internal locus of control), that the individual is skilled enough to create outcomes that they want (self-efficacy), and that they could achieve desired outcomes if they chose to apply the skills they possess (outcome expectations) (Wehmeyer et al., 1997).

Self-realized individuals have knowledge and understanding of their own set of strengths and limitations, and interact with their environment in a way that capitalizes on this knowledge (Wehmeyer et al., 1997). They use personal experience and feedback from significant others and their environment to develop their sense of self.

Having SD is widely recognized as a component of positive life outcomes in children, adolescents, and adults with and without disabilities, (Nota, Soresi, Ferrari, & Wehmeyer, 2011; Shogren, 2015; Shogren, Wehmeyer, Palmer, & Paek, 2013; Wehmeyer & Palmer, 2003). As mentioned in the introductory paragraphs, Wehmeyer (2005) strongly highlights that the development of SD skills in people with severe disabilities is often regarded as futile given severe enough difficulties in adaptive behavior. However, Wehmeyer argues SD skills are important regardless of disability status as someone can make self-determined decisions with assistance, work toward a goal they have chosen with guidance, and these incremental increases of SD still lead to positive outcomes in an individual’s life. Freedom to live with dignity is a human right as defined by several organizations including the United Nations (UN General Assembly, 1948), and as such all efforts should be made to encourage a person to choose for themselves what they want.

Given the recursive and iterative nature of skill development, the development of SD is inherently a product of increasingly complex interactions between an individual and their environment. The cornerstone of the PPCT model (Bronfenbrenner & Morris, 2006) that frames the current study is, in essence, the same concept--that development greatly occurs from the interactions the individual has with their environment. The ways in which SD develops lends itself easily to being understood within the PPCT framework.

PPCT model and SD. Children and adults with disabilities gain SD through interaction across the multiple strata of the PPCT model. Personal attributes, environmental characteristics such as school setting and the opportunity for SD skill practice, and culture each play important roles in SD development. The development occurs over time and with increasingly complex interactions, or processes, between the individual and their environment.

Additionally, the actions, thoughts, and feelings of an individual as driven by their own volitional motivations impact the person's environment. The person governs which settings and to which degree attitudes and behavior will be exhibited. The individual acts on the environment using the available knowledge, skills, and beliefs to reach desired goals and outcomes. Thus, it is the interaction between the individual and the environment that drives the development of SD skills (Nota et al., 2011; Shogren, 2015; Shogren, Wehmeyer, Palmer, & Paek, 2013; Wehmeyer & Palmer, 2003). As such, the person must have the *opportunity* and *capacity* to act in a self-determined way. Without support, those with a disability may not have the opportunity and capacity required to participate in this process. The reciprocal process between all levels of influence on a child's development required for SD further solidifies the need for a systemic approach to understand its development, such as that of the PPCT model.

Recent research supports the application of the PPCT model in understanding and researching the development of SD. Shogren (2013) extensively reviewed SD research from a socioecological framework. Shogren found literature regarding each level of the model in isolation, and very few examples of research that spanned across more than one level. She appealed for research to include more levels of the PPCT model in the design of SD research and in the analysis of the findings. Further, she highlighted the need for systems (e.g., school, disability services/support, family units) to interact more freely with each other to improve SD development, rather than continuing to use the isolating siloed approach common in these systems. Indeed, the concept of integration was attempted to be implemented in policy prior to the Shogren (2013) article. The researchers involved with a national training initiative to enhance SD across the lifespan of people with disabilities funded by the U.S. Administration on Developmental Disabilities in 2008 chose a five-level socio-ecological approach to frame their work, with a focus on the interactional process between the person and the environment (Walker et al., 2011). A group of researchers studying improving SD in individuals with ASD also called for the use of the socioecological approach in applying the interventions they recommended (Wehmeyer, Shogren, Zager, Smith, & Simpson, 2010).

Understanding SD from the PPCT framework is ideal for examining the experiences and development of SD in children with FASD given the varying presentation of symptoms and multifacted and complex circumstances from which the symptoms occur. As many possible influences on the development should be considered in order to understand the children's SD development and to then find areas to target and potentially intervene. Attention to the child's opportunity and capacity is imperative.

Opportunity and capacity for SD can often be analogized with the environmental and the individual-level characteristics that influence SD. In many of the examples and studies illustrated below, the process between the opportunity and capacity of the participants to practice SD plays a large role in their outcomes. The studies are divided by environment and individual characteristics based on the primary variables investigated, though reciprocal interactions between environment and personal characteristics are explored whenever relevant.

Individual characteristics that influence SD. Several different individual characteristics that can impact SD (Nota et al., 2011; Pierson, Carter, Lane, & Glaeser, 2008; Shogren, Wehmeyer, Palmer, & Paek, 2013; Wehmeyer et al., 2011). Namely, age, race, and gender have been investigated, with race generally accounting for little significant variance in SD; however, divergence occurred when individual families or broad cultural differences expected different levels of autonomy from a child by a certain age (Shogren, 2013). With respect to the impact of age on SD, the older a person is the more autonomy (though not necessarily SD) the individual is reported to have (Wehmeyer & Garner, 2003). Findings on the influence of gender on SD are equivocal; American-based studies have shown either no gender differences in SD (Wehmeyer & Garner, 2003), or that females tend to have higher self-reported scores of SD (Lee et al., 2012; Shogren et al., 2007), while an Italian-based study found males to have higher SD scores (Nota et al., 2007). The moderating variables of age, race, and gender appear to be highly influenced by cultural expectations; as such, a PPCT model is best used in understanding their influence within context. Other variables such as disability status, cognitive ability, adaptive behavior, and self-regulation are further reviewed here.

FASD and other disability labels. Disability label or status is important to consider within the PPCT model as the label or symptoms of the condition may influence at the microsystem level how the individual and those in their environment behave and interact with each other. Children with FASD, for example, would benefit from learning, practicing and attaining SD even when they require considerable support to do so. The point of developing SD skills is not that an individual who needs support no longer receives support, it is that the individual can behave volitionally so they can more meaningfully participate in all aspects of society. However, to date there are no studies that address SD in those with FASD within the literature. SD development and skills in people with other disabilities have been explored, but rarely outside of intellectual disability, which is discussed in the cognitive ability section.

Individuals with ASD can have difficulty achieving SD due to characteristic limitations in social communication and interaction, though have been shown to develop skills that improve their ability to behave with SD with support (Wehmeyer et al., 2010). Carter et al. (2006) found differences in SD expression in youth with a LD compared to youth with an emotional disturbance. A more recent analysis compared four aspects of SD (autonomy, self-realization, self-regulation, and psychological empowerment) in children diagnosed with ASD, LD, or intellectual disability (Chou, Wehmeyer, Palmer, et al., 2017). The LD group exhibited higher scores than the intellectual disability and ASD groups. Those in ASD and intellectual disability groups did not differ on measures of self-realization, self-regulation, and psychological empowerment. Children with ASD were rated lowest in autonomy. The researchers highlighted the importance of ensuring children with ASD be given opportunities to practice autonomous behaviors in school settings.

The differences in three aspects of SD (autonomy, psychological empowerment, and self-realization) between youth diagnosed with varying types of disability were investigated in a national, longitudinal study in America (Shogren, Kennedy, Dowsett, & Little, 2014). The types of disabilities were collapsed into six categories based on similarities and differences in latent means and variances. The categories consisted of high incidence disabilities (i.e., learning disability, speech or language disability, emotional disturbances, and other health problems), sensory disabilities (an amalgam of hearing and visual impairments), cognitive disabilities (a combination of multiple disabilities, deaf-blindness, ASD), intellectual disability, traumatic brain injury, and orthopedic problems. There were significant differences between the youth within these six disability categories in autonomy, psychological empowerment, and self-realization; however, there was variability within the categories as well. The findings suggested that while disability status can influence how these elements of SD are exhibited by youth, other factors must be considered to obtain a full picture of how youth with disability develop SD.

Cognitive ability. Studies have suggested that lower cognitive functioning can translate to lower levels of SD (Nota et al., 2011; Shogren et al., 2007; Wehmeyer & Garner, 2003; Wehmeyer et al., 2012); however, SD is not as highly dependent on cognitive ability as one might assume (Heller et al., 2011; Wehmeyer et al., 2011; Wehmeyer & Palmer, 2003). Wehmeyer and Garner (2003) concluded that there was a case against intelligence as a primary predictor of SD given that in their study, scores of autonomous behaviors were not significantly different between groups of individuals with either severe, mild, or no intellectual disability. The opportunity for choice-making was seen to have a pivotal role in the individual’s overall SD scores. Further, it has been repeatedly shown that students with developmental and intellectual disabilities can gain and use SD skills (Heller et al., 2011) and that these students have more positive outcomes in adulthood (Heller et al., 2011; Wehmeyer et al., 2007), suggesting that SD skills continue to be used by people with disabilities long after instruction. Additionally, it has been strongly contended that SD is a function of opportunity and supports, along with capacity (Nota et al., 2007; Shogren et al., 2007). In fact, Wehmeyer et al. (2007) have posited that the assumption that a person cannot gain SD skills because of the limitations inherent in their disability negatively influences access to opportunity and supports. As is the trend in SD research, an individual characteristic, even one as seemingly pervasive as intellectual capacity, cannot explain or account for the variance in SD development alone.

Adaptive behavior. A person's ability to behave in a way that is adaptive to varying situations is integral to how well that person will function in day-to-day life. Some basic examples of adaptive behavior include being able to obey rules and avoid victimization, the ability to use computers/telephones/smartphones, and understanding of the concepts of money and time (FAQ on AAIDD, 2017). People with FASD often have severe limitations in their ability to adapt to different scenarios (Edwards & Greenspan, 2010). The scant research involving adaptive behavior among people with a disability is often negatively skewed by interpretations that foster disempowerment. However, there have been some studies measuring adaptive behavior in relation to the development of SD.

For example, Stancliffe et al. (2000) asked 74 adults with an intellectual disability to participate in a study investigating the adult's personal control (i.e., SD) encompassing several variables across the strata of bioecological development. Specifically, their community residential setting status was identified as either semi-independent with minimal staff involvement, fully staff-supported, or intermediate care facilities that were publicly funded and thus had restrictions on such things as food offerings and leisure activities. Variables such as how much guardianship the adults were assigned, their income, and their personal characteristics (i.e., IQ, age, gender, cultural background) were measured. Competencies related to SD were measured through adaptive and challenging behavior rating scales; the participants' attitude, knowledge, and skills related to SD as reported by proxy (staff) respondents were also assessed. Information regarding staff performance (as measured by supervisors), staff's self-perceived autonomy at work, staff attitudes toward people with intellectual disabilities, staff-to-client ratio, and the clients' social network were gathered.

The authors also found (Stancliffe et al., 2000) that living unit size was correlated with adaptive and challenging behavior; an increase in the number of residents in a unit saw a decrease in adaptive behavior and more challenging behaviors. Additionally, those participants with the highest adaptive behaviors had the least restrictive environments and staff with the most positive views regarding intellectual disabilities. The attitudinal differences between staff in different environments were dependent on the participants' level of adaptive and challenging behaviors. Hierarchical regression analysis was conducted to investigate the level of variance explained by each block of variables (i.e., adaptive and challenging behaviors, SD competencies, living environment); each block of variables was determined to have independent influence on personal control. Overall, SD competencies and adaptive/challenging behaviors jointly were seen to have the greatest influence on personal control.

In several studies, a person's adaptive behavior appeared to predict proxy respondents' perceptions of that person's general engagement in meaningful activities. Namely, Perry and Felce (2005) found that proxy measures of QoL appear to be related to adaptive behavior. Mansell, Beadle-Brown, Macdonald, and Ashman (2003) found that individuals with a learning disability living in small community homes' adaptive behavior was a predictor for the residents' level of engagement in meaningful endeavors; of note, the residents' problem behaviors were not found to be significantly related to their engagement in consequential activity. Felce, Lowe, and Jones (2002) measured the adaptive behaviors of 97 adults with intellectual and/or developmental disabilities living in residential facilities and found that higher adaptive behavior scores were correlated with the residents' level of social engagement with staff and other residents.

Individuals with FASD have marked difficulties in adaptive behavior, including regarding areas related to social intelligence such as gullibility, and areas of self-regulation such as impulsivity and difficulty with organization (Edwards & Greenspan, 2010; Fast & Conry, 2004; Khoury & Milligan, 2016; Kodituwakku, 2009). Self-regulation skills are necessary for SD; as well, self-regulation is one of the four essential components of SD (Wehmeyer et al., 1997). As such, they have been empirically investigated for their influence on SD development.

Self-regulation. One essential characteristic of SD, self-regulation, has gained attention in research with regard to its influence on overall SD development (Chou, Wehmeyer, Palmer, et al., 2017; Martin et al., 2003; Pierson et al., 2008). Self-regualtion has been linked to school readiness in young children (Blair & Raver, 2015). The link was thought to be due to the new social needs at this stage of life, including maintaining attention and focus on the teacher and making and keeping friends. A child with weaker self-regualtion skills than their peers will have more striking emotionality (e.g., outbursts, reactions outside the norm for their age) and difficulty monitoring their social behavior; they will thus likely have difficulty fitting in. Poor self-regulation is also connected to weaker academic performance as children age (Edossa, Schroeders, Weinert, & Artelt, 2018). One study investigated the SD of students with emotional disturbance or a learning disability. The participants were assessed for social skills, problem behaviors, and capacity and opportunity for SD by their teachers (Pierson et al., 2008). Being perceived to have poor social skills resulted in diminished capacity scores, though problem behaviors were not found to predict SD outcomes. Opportunity scores were not impacted. These findings suggest that social skills, an area difficult to achieve without some level of self-regulation, influence teachers' perceptions of students' capacity.

Martin et al. (2003) completed a small study in which eight students with diabilities (e.g., emotional and behavioral problems) were taught self-regulation skills such as planning, scheduling, evaluating progress, and adjusting efforts over time. They found that the students' academic success improved with the intervention. Further, Carter et al. (2006) found that adolescents with emotional disturbance self-reported they were less likely to have opportunities for learning and practice of SD skills than children with a learning disability. Their parents agreed with their reports. Thus, it is imperative that self-regulation be considered in the development of SD for children with all kinds of disabilities. Indeed, Chou, Wehmeyer, Palmer, et al. (2017) encouraged the teaching of self-regulation skills to children with ASD to bolster their overall SD.

Overall, the individual characteristics of disability status, cognitive ability, adaptive behavior, and self-regulation described above appear to influence a person's SD development in various ways and magnitudes. It was shown that many individual characteristics can be targeted for intervention such that difficulties can be addressed and existing strengths can be fostered to create measurable increases in skill development. These findings further reinforce the PPCT framework of SD development given that the environment a person is in can provide opportunities to overcome or build upon characteristics commonly perceived to be generally static (i.e., disability status, cognitive ability, adaptive behavior, and self-regulation skills). The discussion now turns to the aspects of a person with a disability's environment that have been studied regarding influence on SD.

Environmental influences on SD. The environment a person lives in and the interaction between it and the individual's characteristics undoubtedly play a role in an individual's SD skill development (Shogren, 2013), though the specific characteristics of a person's environment have yet to be fully discussed. Environmental influences on SD discussed here include the classroom and school environment, teacher perceptions and skill level, community and support system, and policy. Shogren (2013), using Bronfenbrenner's (1979) socioecological model to frame her work, identified these factors as important meso- and macrosystem characteristics in her review of influential variables on SD development.

Classroom and school environment. In the field of education, teaching SD skills to youth with a disability is considered a best practice (Wehman, 2012) as it means better QoL (Wehmeyer & Schalock, 2001) and increased independent living and employability after high school completion (Wehmeyer & Palmer, 2003). There is strong evidence that SD interventions in youth with a developmental or learning disability is effective and is thus a worthwhile endeavor in pedagogy (Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2010). Further, a student's active participation in Individual Education Plan meetings (as opposed to mere attendance) increased SD skill ratings (Shogren, Wehmeyer, Palmer, & Paek, 2013).

Interventions geared toward increasing SD in individuals with a developmental disability who are later in their adolescence, have been shown to improve post-high school success as measured by employment and community access (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2013). The findings are compelling given that they encompass a follow-up of a large sample size (N = 779) of students who were randomly assigned to intervention or control group. The study provides more evidence that skills geared toward SD can and should be taught at all ages regardless of the person's current level of functioning.

However, the classroom environments where children can learn and practice SD skills vary drastically. Zhang (2001) found that students with disabilities were provided with more opportunities to exhibit and practice self-determined behaviors when they were educated in a separate classroom rather than in an inclusive setting. In his article, Zhang described that it may be more challenging for students with disabilities to behave in a self-determined fashion in a regular classroom because, due to time and resource constraints and lack of experience, regular education teachers are less able to create opportunities for the students with disabilities to self-determine. But as Shogren et al. (2007) report, Zhang's study measured the frequency of behaviors associated with SD. Thus, it is possible that the students in the study had equivalent SD across groups but simply expressed the behaviors at different rates in the different settings. Further, Shogren, Wehmeyer, Palmer, and Paek (2013) found that the number of hours spent in a general education classroom was a significant predictor for increased level of SD in children with disabilities. Overall, most researchers agree that an inclusive educational setting is ideal to provide opportunities for children and adolescents to learn and practice SD skills (Agran, Cavin, Wehmeyer, & Palmer, 2006; Palmer, Wehmeyer, Gipson, & Agran, 2004).

The research thus suggests that students with disabilities require a classroom setting that enables the teaching of SD skills and the practice of these skills with other children. The provision of the most opportunities for SD development appears to be related to access to a general education classroom, though the teacher's level of skill and their perceptions of SD and disabilities undoubtedly influence the classroom environment as well.

Teacher perceptions and skill level. There is evidence that teachers in North America do not always teach skills related to SD (e.g., choice making, problem solving, goal setting, self-advocacy and leadership, self-management, and self-awareness) to children with disabilities, despite favorable attitudes toward the construct (Cho, Wehmeyer, & Kingston, 2011b; Shogren et al., 2007; Wehmeyer, Agran, & Hughes, 2000). For example, in one large-scale survey study of American elementary school teachers, respondents were overwhelmingly in support of teaching

SD skills to all children (Cho, Wehmeyer, & Kingston, 2011a). However, when asked specifically what barriers they face in teaching these skills, they reported some child-centered barriers such as belief that the children were too young to learn SD or that the children had more pressing needs. Most notably, when it came to students with disabilities, 12.3 % of general education teachers and 5% of special education teachers reported the students would not benefit from training in SD skills, data which suggests that the teachers' lack of exposure to children with disabilities increases perceptions of child-centered barriers to the development of SD skills in the classroom (Cho et al., 2011a). Conversely, a follow-up study from the same researchers found no differences between general education teachers and special education teachers' perceptions of the significance of SD instruction (Cho, Wehmeyer, & Kingston, 2013), though there were limitations in the study design such as dichotomous response options on the questionnaires used in the study and low response rate.

Pierson et al. (2008) examined teacher perceptions of the capacity and opportunity for the development of SD skills in students with either emotional difficulties or learning disabilities. The researchers included a measure of social skills to understand what role this individual characteristic had. According to teachers, the students' capacity for developing SD skills was significantly related to social skills, not disability label. The opportunities for SD skill development were equal in all groups. It is logical that social skills can constrain a student's ability to participate effectively in SD skills such as being a self-advocate, set and move toward goals, and using self-reflection to adjust actions to reach goals. However, this study failed to account for teacher attitude toward disability and teacher experience in different educational settings.

Additionally, Peeters, De Backer, Kindekens, Triquet, and Lombaerts (2016) found that teachers perceived several student-based characteristics as either detrimental or beneficial to the development of self-regulation, an essential characteristic of SD in the classroom. Most teachers felt their ability to teach self-regulation skills to students was obstructed by cognitive capacity, socio-economic background, or language or learning disorders. As mentioned, Cho et al. (2011a) did account for teacher experiences in their study of SD skills in different disability populations and found that more diverse experiences were related to teaching more strategies to increase SD.

With respect to the application of SD skill instruction in classrooms, a recent study conducted in Taiwan showed that both special education and general education elementary school teachers teach students skills related to SD (Chao & Chou, 2017). There were differences in the frequency and type of skill the teachers would foster in their students depending on the setting in which they were working. General education teachers taught SD skills in a relatively balanced manner with the most emphasis on psychological empowerment, while those in special education settings tended to focus on autonomy and self-realization and less on psychological empowerment and self-regulation. The findings reflect the teachers tailoring their instruction to needs of different populations.

Community and support systems. Wehmeyer et al. (2011) discussed the discrimination, oppression, and segregation those with disabilities often encounter in education, community life, and employment. While adults with developmental disabilities have been shown to set and achieve goals and function more independently when provided with opportunities for SD (Wehmeyer & Palmer, 2003), people with disabilities tend to live in restrictive environments, and may lack opportunities to make choices. In a highly restrictive environment, challenging behaviors may be bids to exercise personal control. There is also a feedback loop where lower

SD skills result in more socially inappropriate (i.e., challenging) behaviors, and the more socially inappropriate behaviors one exhibits, the more restrictions and thus fewer opportunities one will have to develop more effective behaviors. This is a prime example of a process as per the PPCT model; the environment and the individual are interacting in such a way to impact the development of the individual. In this case, unfortunately, the individual's development is dampened rather than encouraged.

As previously mentioned in the paragraphs regarding the impact of prejudice on FASD, FASD support groups are scarce and not always well-attended. The sense of isolation and secrecy is thus compounded for those impacted by FASD. While we know that access to community-based employment and housing increases levels of SD in adults with disabilities (Stancliffe et al., 2000), how these factors influence SD skill development in children is currently unknown. However, a supportive community and sense of pride and belonging would likely improve opportunities for SD if viewing the situation from the perspective of the PPCT model. The child with connections and support within the community is more likely to feel comfortable practicing their SD skills outside of school or home (e.g., making food choices at a restaurant or going to a park with minimal supervision).

Policy and public perception. Disability-related public policy impacts significantly on even basic definitions of what a disability is, as well as on if, when or how people with a disability access and interact with services (Shogren et al., 2009). Children with FASD are often neglected at the policy level by schools and education boards (Bredberg, 2011; Duquette & Orders, 2010), which limits their opportunities. As such, recent research has called for more systemic acknowledgement and support for children with FASD in schools (Millar et al., 2017).

The public's general perceptions of those with disabilities interact with policy (Shogren et al., 2009). Based on these interactions, people with a disability experience effects such as greater or lesser inclusion in the community (Shogren et al., 2009). When the public perception of a condition is negative, people with that condition are likely to experience negative bias or stigma that impacts on their daily lives at all levels of the PPCT model. As has been discussed, those with FASD encounter stigma for several reasons and across several settings (Armstrong & Abel, 2000; Bell et al., 2016; Hunting & Browne, 2012; Tait, 2000). Policy for and public perceptions of FASD appear to require a paradigm shift to better serve this population. As SD has been shown to be so helpful for people with other disabilities (Wehman, 2012; Wehmeyer et al., 2010), it is particularly important that people with FASD gain access to supports to improve their SD.

Summary of SD. Overall, SD is a multi-faceted concept that is best approached through the PPCT model in research to more completely understand what is beneficial for children and adolescents who require support in developing their SD skills. There are several environmental and individual characteristics that interact to enable a person to develop SD, and the interaction between them is important to consider within the PPCT framework. SD is especially important to study in FASD because, aside from the fact that to date no research has addressed the topic, those with the diagnosis would truly profit from learning and practicing the skills required for SD behavior. Not only would they likely gain more independence, their QoL would increase.

There is evidence that QoL and SD are inextricably connected (Schalock, 2004; Wehmeyer & Schalock, 2001). Indeed, SD is considered an aspect of having QoL (Schalock et al., 2016). Most relevant to the current discussion is how people with disabilities who had opportunities for SD reported levels of QoL higher than those who did not (Wehmeyer &

Schwartz, 1998). In the next section, a discussion of QoL as a concept will take place. The implications on QoL from developing SD in children with disabilities will be explored.

Quality of Life

A positive QoL is a core feature of many treatment interventions across health-care fields, especially from within Western culture (Van Hecke et al., 2018). However, QoL is a complex construct. A common and objective understanding of what constitutes QoL is necessary to communicate where a person has strong QoL, where a person may benefit from intervention, and how to intervene meaningfully. Conversely, without a person's subjective account of what is important to them and what personal, interpersonal, and environmental characteristics they require to feel fulfilled, the concept of QoL would be reduced to a one-size-fits-all mold wherein only those needs and values fitting the universal definition would be considered. As with many concepts in human psychology, over-reliance on either objective or subjective measures of QoL is problematic, and as such, evaluation from different perspectives is valuable (Van Hecke et al., 2018). While not always explicitly stated, some researchers draw from the PPCT model in their conceptualizations of QoL, and ultimately it is the bioecological understanding of QoL that is used in this study. There are several types of QoL that could be explored; however, the following review focuses on children's QoL research and QoL research within disability studies.

There are three main approaches to conceptualizing children's QoL: (a) health-related QoL, (b) social indicators, and (c) subjective well-being (SWB) (Wallander & Koot, 2016). The definitions of each concept are varied between and within academics and global policy-making organizations such as the World Health Organization (WHO) (Wallander & Koot, 2016). Briefly and generally, Wallander and Koot define health-related QoL as a person's experience of their social, mental, and physical health status, as well as the objective and subjective impact of their illness on their overall functioning. Health-related QoL was not originally developed to encompass an individual's overall QoL given that most scholars and global policy-makers agreed that while important, QoL is not only defined by the absence of disease (Van Hecke et al., 2018; Wallander & Koot, 2016). However, the majority of QoL research is focused on health-related QoL, in part due to a tendency for its use in medical outcome studies. In tandem with this, most QoL instruments only measure health-related QoL. The range of what the instruments include is broad, ranging from a tight focus on the social, mental, and physical domains of health, to the inclusion of up to 17 other domains (e.g., body image, self-esteem, autonomy, school/work, leisure, family, autonomy) (Wallander & Koot, 2016). The broader measurements are an excellent means to understanding the effectiveness of an intervention or treatment; however, the basic conceptualization of health-related QoL is the presence or absence of illness. Health-related QoL measures are thus not sufficient in understanding all aspects of what makes a child's life positive and worth living.

Social indicators of QoL are quantitative, objective circumstances that communicate a good life as dictated by the societal norms of a geographical or cultural group (Wallander & Koot, 2016). For example, in children and youth some factors that indicate QoL may include infant mortality, access to and provision of health care and vaccinations, mental health diagnosis, familial and/or residential stability, classroom size, substance use, or involvement with law enforcement (Wallander & Koot, 2016). The approach has been traditionally focused on survival statistics, though has expanded to supporting children's ideal development as well as survival.

Measuring QoL in this manner results in a population-level understanding of children's status on a variety of metrics of optimal development. This also aids in keeping governments and organizational bodies accountable for the policies that they implement. However, measurements of social indicators of QoL tend to exclude positive elements in the children's life such as resiliency, and categorically do not account for the child's subjective experiences, thus limiting their use in understanding individuals. Further, the indicators are generally reflective of the ideals of a given society, which is again a potential benefit in understanding a greater population but not an individual.

Subjective well-being (SWB) is, as the name implies, a person's sense of satisfaction with their life (Wallander & Koot, 2016). It is someone's level of perceived happiness and whether they feel their life has meaning. If one is from a Western culture, the concept can be thought of as a human life's ultimate purpose (Wallander & Koot, 2016). According to Wallander and Koot, QoL measures based on SWB were originally intended to supplement social indicators, though their positive focus (i.e., measuring degrees of happiness rather than absence of negative circumstances) is attracting more attention in scientific studies. Measures of SWB generally focus on the child's life satisfaction and happiness within and across domains (Wallander & Koot, 2016). While the clear advantage of using SWB measures is its direct approach, the underlying concept of SWB is still under debate. Currently, SWB is typically measured from both specific domain and global perspectives as this approach provides relevant information in understanding the respondent's overall state. Some researchers (Schalock et al., 2016; Wallander & Koot, 2016) posit that there are fundamental and essential elements of life quality that can be universally applied to all children.

One of the world's leading authorities on QoL presents the concept as a set of eight core principles (Schalock, 2004; Schalock, Bonham, & Verdugo, 2008; Schalock et al., 2016). The principles included are (a) physical well-being, (b) emotional well-being, (c) material well-being, (d) interpersonal relationships, (e) personal development, (f) social inclusion, (g) rights, and (h) self-determination (Schalock et al., 2016).

Overall, the concept is seen similarly across and within cultures (Brown, Schalock, & Brown, 2009); however, socio-political limitations and differences in basic life requirements (education, health care, food, shelter) alter perceptions of QoL. Additionally, variations between people and personalities result in interests, values, and hobbies that differ in importance to different people (Cummins, 2002). For example, one person may assign their career as the highest priority and any upward mobility may give them great pleasure, whereas another person may consider gains in their personal fitness to be a greater source of joy than any career advancements might. Thus, it is to the advantage of anyone researching and measuring QoL to take personal and environmental context into consideration.

Indeed, Schalock (2004) himself incorporates the bioecological model founded by Bronfenbrenner (1999; Bronfenbrenner & Morris, 2006) in his recommendations for measuring QoL. To elaborate, Schalock (2004; Schalock et al., 2016) suggests a methodological pluralism for measuring QoL. This translates to a look at each one of the micro (personal, subjective), meso (objective, formal assessments of elements of QoL including SD), and macro (social indicators such as standard of living, access to resources, impact of policy and law) systemic levels.

Research of QoL in the child FASD population has not yet been conducted. There is evidence that QoL is lower amongst children who have a disability. For example, in a study comparing children newly diagnosed with a LD to their typically developing peers, several elements of QoL were identified as being significantly different between groups (Ginieri-Coccossis et al., 2013). Using the KINDL-R, Ginieri-Coccossis et al. (2013) measured the students' perceptions of their QoL across six domains: family life, school functioning, relationships with peers, emotional well-being, self-esteem, and physical health. Specifically, poorer satisfaction with social relationships and family life, lower self-esteem, and lower emotional well-being were reported in the LD group. Surprisingly, no differences were found between groups on the school life domain.

The impacts of disability on QoL spread to the children's families as well. A large-scale, nationally-representative study based in the United States was conducted to review and compare families' levels of QoL when families included children with either a diagnosis of ASD, ADHD, or no diagnoses (Lee, Harrington, Louie, & Newschaffer, 2008). Comorbid disorders were allowed in the two former conditions though any children with an ASD diagnosis were included in the ASD group regardless of their ADHD diagnostic status. Families with a child with ASD reported the lowest QoL, followed by families with a child with ADHD; families with children who were typically developing therefore reported the highest QoL.

Maladaptive behaviors such as internalizing behaviors in males and externalizing behaviors in males and females were linked to lower life satisfaction in young teens (Lyons, Otis, Huebner, & Hills, 2014). Reduced cognitive engagement in school and negative attitudes related to future schooling were found in middle school teenagers who reported lower life satisfaction (Lewis, Huebner, Malone, & Valois, 2011). Martin, Huebner, and Valois (2008) found that increased inter-relational victimization was predicted by lower scores on a life satisfaction measure in adolescent participants from.

Adaptive behavior was not seen, however, as predictive of subjective perceptions of QoL in individuals with an intellectual and/or developmental disability living in a residential facility (Perry & Felce, 2005). Adaptive behavior scores had been highly predictive of objective measures of QoL (i.e., higher scores on the adaptive behavior measure begat higher scores on the proxy QoL measure). While differences between subjective and objective (i.e., proxy) measures of QoL in individuals with cognitive or communication impairments is an old debate in QoL research (Van Hecke et al., 2018), it is not the focus of this discussion. Rather, what the specific finding in research by Perry and Felce (2005) relating to adaptive behavior suggests is that individuals with lower adaptive behavior scores do not necessarily perceive their QoL to be lower than others with higher abilities or functionality. There are several ideas for why this finding occurred. The authors present arguments related to homeostasis, the well-tread concept that a person's SWB fluctuates only so much in response to positive and adverse life events (Cummins, 2005). The general population's SWB rests at 70-80 on a scale of 0-100, and those with intellectual disabilities report similar ranges (Cummins, 1995). It is possible that those with disabilities or other disadvantages adapt to having fewer available resources. However, there is evidence that those with disabilities *do* experience lower QoL both subjectively and objectively (e.g., Ginieri-Coccossis et al., 2013), with a litany of negative consequences.

Methods of improving QoL in children and adolescents with a disability (be it physical, learning, emotional, or developmental in nature) have been put forward in the literature. Namely, increasing students' access to and inclusion in school and their community was considered imperative in one study (Edwards, Patrick, & Topolski, 2003). A family-focused approach to intervention was the most significant predictor of increased family QoL for families of young children aged 3-5 with a developmental delay or disability (Davis, Watson, & Cunningham-Burley, 2000). In a systematic review of several studies involving children and adolescents with ADHD, the youth's QoL improved when their symptoms of ADHD were treated (Danckaerts et al., 2010). Thus, it is entirely possible to improve upon a child's QoL despite any micro- or mesosystemic-level characteristics that detrimentally impact QoL.

Summary of QoL. Children's QoL is a widely researched area, though of the three main types of QoL measured (i.e., health-related, social indicators, and SWB), health-related QoL is the most prominent due to its connection with medical treatment outcome studies (Wallander & Koot, 2016). Regarding people with disabilities, QoL scholars recommend taking a bioecological approach and obtaining information from both objective and subjective sources to best understand the various factors that impact on a person's QoL (Schalock et al., 2016).

In the current study, QoL was explored through means of questionnaire data and cross-referenced with information from photographs, a semi-structured interview, and with measures of SD and adaptive behavior. These data represent elements of the participants' micro and mesosystems as well as the processes that impact their development. Specifically, the child's individual characteristics, opinions, and daily living skills represent factors at the microsystem level. Relationships between the children and their environments were explored as processes, and mesosystemic level interactions between teachers and parents were also analyzed for their potential impact.

Purpose of the Study

The current study explores SD in children with FASD, a population that is rarely given voice in matters relating to their education. SD is a multi-faceted construct and FASD is a complex disorder that presents in a variety of ways. As such, information must be gathered from a variety of sources and levels as per the PPCT model (Bronfenbrenner & Morris, 2006). The children's photographs and brief narratives regarding their self-perceived challenges and successes at school are examined to gain an understanding of the children's SD. Their self and proxy-identified goals and their progress toward meeting these goals can provide a nuanced understanding regarding the SD of these children. Knowledge of the children's functioning at home and school as obtained through standardized measures of adaptive behavior further informs understanding of the children's SD, their individual characteristics, and the contexts under which the children were choosing what to photograph. Similarly, the findings from QoL questionnaires further inform our comprehension of the children's inner life, personal characteristics, as well as their environments (i.e., micro, meso, and macrolevel influences). The data are analyzed qualitatively from within the PPCT framework to explore elements that may be impacting the SD of the children with FASD.

Thus, one central exploratory question is posed. Namely, what can we learn about the SD of children with FASD using information from a variety of perspectives and sources of data? Secondary questions relate to what themes arise in the photographs and brief narratives associated with the child participants' most successful and most challenging experiences at school, and when analyzed using the PPCT model, whether the information from the questionnaire data on the children's adaptive behavior, QoL, and SD support these themes.

Methods

The present study explored the experiences of child participants diagnosed with FASD as they may relate to SD. This section outlines the philosophical rationale, methodology, and procedure of the study. Participant information and demographics are provided, and the data analysis process is described. Ethical considerations and validity processes are also discussed.

Qualitative Research Design

Qualitative research generally seeks to understand phenomena through the perspectives of the study's participants; it seeks to provide an in-depth understanding of a complex, multi-faceted issue (Creswell, 2014). The purpose of the current study was to gain a deep understanding of the children diagnosed with FASD's experiences as they pertain to SD at school from within a PPCT framework. At the time of writing, virtually no literature existed that focused on children with FASD's experiences as told from their own perspectives. The only qualitative study found which focused on children with FASD had a sample size of seven children and their guardians for a total of 11 guardians (Duquette & Stodel, 2005). All participants completed questionnaires developed by the researchers and interviewed regarding their school experiences. However, only two of the children in the study were under 18 years of age; the remaining five participants were adults who were asked to reflect on their childhood experiences in elementary and secondary school (Duquette & Stodel, 2005). Thus, a study having children with FASD as the primary source of qualitative information has yet to be conducted. Further, no studies have been conducted investigating the SD of children with a diagnosis of FASD, and none have used a PPCT framework to understand their data. An exploratory research approach that honored the child participants' views and allowed for flexibility and depth in learning about their SD was required. Qualitative research also provides the opportunity to explore in more detail and intensity the context in which the phenomena take place, and how the processes between different factors might influence the children's SD, which fits nicely with the PPCT framework.

While there are several approaches a researcher can choose from within the qualitative research tradition, the most aligned with the current study is that of a descriptive phenomenological approach (Bloomberg & Volpe, 2012; Englander, 2016; Giorgi & Giorgi, 2008). Phenomenology is the study of a small group's experience--it is the experience, or the phenomenon's essence that is under investigation. A small number of participants is sufficient, generally between three and ten, as the researcher is to extensively engage with each person's data to find meaningful relationships and patterns within the information (Creswell, 2014).

These patterns and relationships, known as essential themes, are interpreted by the researcher who addresses inherent bias in the analysis through acknowledging the influence of their own knowledge and experiences. The data are interpreted in a way that is unique to the participants' experience, or, there is an attempt to view the data from the lens of the participants' experience during analysis. Hence, the essence of the phenomenon is derived from the data and reported upon. Information resulting from the data is categorized and described in a way that will facilitate the understanding of the participants' experience.

While these steps are common in both descriptive and interpretive phenomenology, interpretive phenomenology requires a focus on researcher reflexivity throughout the process (Giorgi & Giorgi, 2008). In descriptive phenomenology, the researcher first uses the data to describe the phenomenon in concrete terms. A holistic sense of the data set is acquired prior to coding and creation of themes. The researcher refrains from allowing their bias to influence their analysis through focus on the participants' intended messages. Attempts to achieve a reduced researcher bias are made through leaving the data as the participant expressed them until it is time to move forward in describing the overall phenomenon by the creation of themes. Researchers must be aware of their backgrounds and roles throughout the research process, though their acknowledgment of these influences does not need to be explicitly expressed throughout the analysis given that the focus is on the intended meaning of the data and not the researchers' reactions to the data (Giorgi & Giorgi, 2008).

Researcher's Role

My academic background is primarily focused on psychology, and to a lesser extent, education and sociology. At the time of writing, I had over ten years of working in various capacities with children of different ages and abilities, the latter half of which was spent within a professional role as a school and clinical psychologist in training. As such, attunement to participants' descriptions of potential symptoms of disability/distress was acknowledged during data collection and analysis. In terms of understanding FASD on a personal level, I had limited contact with people diagnosed with FASD prior to engaging in the study. However, nine years prior to data collection, I did work with a six-year-old boy who had been diagnosed with FASD as an educational assistant within an inclusive classroom. This child, like many others with FASD, had suffered psychological traumas including placement in foster care. His emotional struggles only exacerbated his symptoms of ARND. For example, he would often have severe behavioral outbursts including throwing chairs and destroying school property. The boy would flee from school when especially under-regulated, even in winter and without a parka. His unpredictability served to alienate him from other children, who clearly did not understand why he was behaving in such a way and felt afraid of him. He despised schoolwork and sitting still; sitting for more than 15 minutes of an activity often resulted in power struggles and escalations. He was eventually switched to a more flexible and understanding teacher's class and was predictably much more successful in that classroom. My experience with this boy highlighted the difficulty and misunderstanding children with the disorder can experience at school, and FASD became a special interest as a result.

One of my roles in this study was as a facilitator. I provided the children with the means for taking the photographs and offered the general topic of what the children could photograph. I also provided loose structure to the conversations with the children about their photographs' content. Subsequently, another role was to model inclusive, empowering interactions with the children to other stakeholders in the children's lives, including themselves. By having the children decide what to photograph and which of their photographs to choose to discuss for the study, their ideas were given weight and importance.

Ethical Considerations

Given the age of the participants and the symptoms of FASD, ethical considerations were numerous. My primary responsibility as the researcher was to respect the rights of the participants; I obtained ongoing assent from the child and consent from adult participants throughout the study. I made all efforts to reduce the power dynamic between myself and the child participants, as a strong deference to me would have likely altered the child's behavior and their level of meaningful participation in the activities. For example, I spent time with the children discussing topics not related to the study and attempted to present myself as equal as appropriate with body language (e.g., sitting beside them rather than across from them). Given that some level of sensitive information was likely to be revealed, confidentiality was ensured prior to any information sharing.

Specific scores and percentile ranks from standardized and non-standardized questionnaires were not shared with child participants, guardians, or teachers because the information was not gathered with intent of clinical application. Further, without context and a complete clinical assessment, the information from the questionnaires could have easily been misinterpreted. The child participants' photographs were not shown to teachers or parents unless the child participant asked me if they could do so. All data were organized under each respective child participant's individual, non-identifiable code that I produced. In other words, all teacher and guardian questionnaires were coded under the same code as the child they were referring to when filling out the questionnaires. Later, I gave each child participant a pseudonym.

Photographs in Research

Over the past decade, there has been a surge toward research *with* children as opposed to research *on* children (Carpenter & McConkey, 2012; Hill, 2006; Tashakkori & Teddlie, 2010). By giving the children a voice through the photograph-taking process, the current study joins that trend.

Using photographs in the current study, I utilized a process called Photovoice. Photovoice is a method of empowering people to document their experience and knowledge through photographs to effect change in a community (Wang & Burris, 1997). To elaborate, it is posited that through the photos, people's experiences offer discussion points that enable participants to be agents of positive change within their community. Photovoice has been used successfully across a variety of settings and cultures (e.g., Baker & Wang, 2006; Brazg, Bekemeier, Spigner, & Huebner, 2011; Mitchell, DeLange, Moletsane, Stuart, & Buthelezi, 2005; Moletsane et al., 2007; Stephenson, 2012; Strack, Magill, & McDonagh, 2004; Virgi, 2011; Wang, Cash, & Powers, 2000; Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004; Wang & Pies, 2004).

Merrick and Roulstone (2011) highlighted the use of photograph-taking in qualitative research with children. In their study, children aged 7-10 were interviewed regarding their experiences with speech and language therapy. Given that the children's strengths lay in areas other than oration, the authors gave them the option of describing their thoughts, feelings, and knowledge regarding their experiences with speech and language pathology using alternate methods such as scrapbooking, picture taking with disposable cameras, and drawing. The children shared their experiences and feelings regarding their communication difficulties. They expressed that requiring assistance with communication can result in negative power dynamics with peers and adults. In relation to speech therapy specifically, the researcher encouraged therapists to reduce the power dynamic between themselves and their clients so that the children would be more likely to have a naturalistic setting in which to practice their speech. The results of the research provided indirect advocacy for the children receiving speech and language therapy.

In Australia, Fitzgerald, Bunde-Birouste, and Webster (2009) used similar techniques to obtain children's views on physical activity, asking typically developing students from kindergarten to grade six to either participate in focus groups, draw, or take pictures of their experience. The visual techniques toward data collection were used to make the tasks more engaging for the students. Similar themes were procured from each type of data collection, thus suggesting the use of photo taking in research creates an engaging and valid option for obtaining information from children regarding their experiences.

The use of photograph taking as a visual data collection method has been noted to be particularly useful for those who traditionally have fewer opportunities to share their experiences due to the tendency of research methods to focus on written or spoken word, such as people with weaker reading ability or communication disorders (Davis et al., 2000; McAllister, Wilson, Green, & Baldwin, 2005). Thus, with respect to the current study, using visual methods allowed for a greater range of students to participate meaningfully and have their experiences heard. Specifically, the participants were guided by the questions, "What is your favorite part of school? It can be anything. Something you are good at, something that makes you feel good." and, "What is hard for you to do at school? It can be anything. Something you really don't like, or something you find really difficult to do." For the purposes of the current study, use of photographic data allowed for a deeper understanding of participants' SD skills and what may influence the development and use of those skills. Please refer to the procedure portion of this section for further detail on how the children took and spoke about their photographs.

Instruments

Two measures were completed by the participants: the KINDL-R measure of QoL (Ravens-Sieberer & Bullinger, 2000), and the American Institutes for Research (AIR) SD scale (Wolman et al., 1994). The AIR and the KINDL-R were also completed by the participants' guardians and the AIR by their main educators. Additionally, the Adaptive Behavior Assessment System - Second Edition (ABAS-2) (Harrison & Oakland, 2008) was completed by the children's guardians and teachers. Each instrument is detailed below.

ABAS-2. The ABAS-2 (Harrison & Oakland, 2008) is a standardized, norm-referenced questionnaire that measures a child's daily living skills (i.e., adaptive behavior) across three domains: conceptual, social, and practical. The three domains combine to create a Global Adaptive Composite (GAC) that can be used as an overall indicator of the person's daily living skills. The conceptual domain refers to a composite of three subtests; communication, functional academics, and self-direction (i.e., independent self-regulation, planning, and organization). The social domain is comprised of the composite of leisure and social skills/ability. The practical domain assesses community use, ability to keep healthy and safe, keep a home in order, and engage in personal hygiene. Typically, both a child's guardian and their teacher will fill out this questionnaire to allow for assessment of the child's behaviors in different settings. Respondents choose between a score of 0 (not able), 1 (never when needed), 2 (sometimes when needed), or 3 (always when needed) in describing the child's ability to perform a skill independently. As compared to cognitive functioning, adaptive behavior is increasingly becoming the area of functioning clinicians refer to in understanding a child's abilities due to the rich, accessible, and pragmatic nature of the construct.

The ABAS-2 was standardized on a nationally representative (according to proportions of race/ethnicity, age, sex, education level, geographic location of respondent, and clinical diagnosis of child found in the United States population in 1999) sample of 1690 teachers and 1670 parents. Internal consistency for the General Adaptive Composite (GAC) ranged from .97-.99, while the adaptive domains ranged from .91-.98. Test-retest reliability coefficients of teacher and parent forms fell at .91 and .93 for the GAC, respectively. Inter-rater reliability of GAC on teacher forms (i.e., two teachers filling out the form about the same individual) was .90, and was .91 on parent forms. Cross-form consistency was lower at .70 for the GAC. Convergent validity of the ABAS-2's GAC was achieved with other measures of adaptive behavior such as at .80 with the Adaptive Skill Composite of the Behavior Assessment Scales for Children, and at .75 with the Adaptive Behavior Composite of the Vineland Adaptive Behavior Scale. Content validity occurred through research of the AAIDD's guidelines regarding the skill areas relevant to independent and successful functioning, then test piloting the questionnaire for clarity of observability of the behaviors related to those skill areas. Factor analysis also showed that the skill areas loaded onto their proper domains as well as to the GAC, and not onto each other.

Use of the ABAS-2 has been previously used in research involving adults (Temple et al., 2011) and in children (Carr, Agnihotri, & Keightley, 2010; Rasmussen et al., 2010) with diagnoses of FASD. It was also used more recently in a small study investigating the effects of medical treatment on children diagnosed with ADHD (Lindblad et al., 2017), as well as in a broader study where proxy measures of adaptive behavior were compared to an individual's cognitive ability and his or her own perception of their adaptive behavior (Arvidsson & Granlund, 2016).

KINDL-R. The KINDL-R (Ravens-Sieberer & Bullinger, 2000) was chosen to assess QoL for its superior suitability within the current study, namely its general adherence to Schalock's conceptualization of QoL (Schalock, 1996; Schalock et al., 2008; Schalock et al., 2016) and thus its fit within the over-arching bioecological theory of development framing the current study (Bronfenbrenner & Morris, 2006). Specifically, Schalock et al., (2016) cited that (a) physical well-being, (b) emotional well-being, (c) material well-being, (d) interpersonal relationships, (e) personal development, (f) social inclusion, (g) rights, and (h) self-determination are each a component of QoL; the KINDL-R address four of these elements (i.e., physical and emotional well-being, interpersonal relationships, and personal development). As such, this measure is contrary to most other children's QoL questionnaires that focus on health-related characteristics and physical symptoms of diseases. There are six subscales on the KINDL-R, each contributing four items to an overall score on 24: physical, emotional, self-esteem, family, friends, and school. Respondents rate their experiences as described by the items on a 5-point Likert scale. The scores are tabulated and transformed to create a value ranging from 0 to 100; the higher the value, the higher the reported QoL. The age range is appropriate for the population desired; other suitable measures had ceiling ages of 12. The KINDL-R offers a parent or proxy version of the measure. The items on the parent version correspond directly to those on the self-report, making for simpler comparisons. Comparisons between child and parent KINDL-R reports have been used in prior research (Rotsika et al., 2011), and have been shown to have strong convergent and discriminant validity (Jafari, Sharafi, Bagheri, & Shalileh, 2014). Significant differences between responses to items on the self and proxy reports were found though were determined to be due to differences between how children and adults interpret the questions (Jafari et al., 2014).

Psychometrically, the questionnaire shows reliability--internal consistency measured by Cronbach's alpha showed values of over .80 overall and at or above .70 for each sub-scale (Ravens-Sieberer & Bullinger, 2000; Ravens-Sieberer, Erhart, Wille, Bullinger, & Group, 2008). Convergent validity with the psychosocial elements of two other QoL measures for children was also acceptable with Pearson $r > .60$ (Ravens-Sieberer & Bullinger, 2000). The analyses were calculated from a sample of over 2500 German children averaging age 12. The KINDL-R has also been validated in Greece (Vidali, Vidalis, Ravens-Sieberer, & Bullinger, 2001) as cited in (Ginieri-Coccossis et al., 2013), Turkey (Eser et al., 2008), Taiwan (P. H. Lee, Chang, & Ravens-Sieberer, 2008), Norway (Helseth & Lund, 2005), and with Serbian populations (Stevanovic, 2009), though in Taiwanese and Serbian participants it was recommended that some items be revised to be more culturally appropriate. A systemic review of 94 generic and disease-specific measures of QoL found the KINDL-R to be one of few measures to have strong reliability, validity, and sensitivity to changes in QoL (Solans et al., 2008). The measure has previously been used in research in children with specific Learning Disabilities (Ginieri-Coccossis et al., 2013), bipolar disorder (Freeman et al., 2009) and in inner-city children with asthma (Montalto, Bruzzese, Moskaleva, Higgins-D'Alessandro, & Webber, 2004).

AIR. The AIR is widely used in research to measure SD, particularly in research that involves children with disabilities (Chou, Wehmeyer, Shogren, Palmer, & Lee, 2017; Shogren et al., 2007; Shogren et al., 2008). The measure contains questions designed to assess both the capacity and the opportunity for SD (Wolman et al., 1994). Specifically, there are three sub-sections of the capacity domain (knowledge, ability, perceptions) and two sub-sections of the opportunity domain (at home and at school). Knowledge refers to the basic knowledge children require to identify a certain barrier to their success and possible solutions toward overcoming the barrier. Ability refers to the skills required to act upon the solution, such as making decisions and plans and then following up on the plans to meet the goal. Perceptions refer to the student's confidence in making and meeting their goals. This includes being able to take some risks, being motivated, and feeling positive and optimistic. The opportunity sub-sections refer to the student's opportunity for SD in each respective environment. It follows that no amount of knowledge, ability, and positive perception will amount to SD skills if the student does not have any opportunity to exercise and apply those skills. The total scores are converted to a percentage.

On both the self-report and the parent form of the AIR, the opportunity score is calculated in the same way as the educator form. The capacity measure on the parent form is only one subdomain which is the equivalent to the ability subdomain of the educator form. The self-reported capacity measure is comprised of both the ability and the perception subdomain equivalents to the educator form. In the current study, each score was converted to a percentage to increase comparability between respondents.

Open-ended questions on each version of the AIR pertain to goals that the child is working toward and how the child is progressing in relation to achieving them. Participants are asked to identify one example of the child's goals, how the child is going about reaching the goal, and how well the child is doing in reaching the goal.

The AIR was created for use with all school-age groups (Wolman et al., 1994). Furthermore, the AIR has self, educator and family versions, providing the chance to assess similarities and differences in perceptions of the participant's capacities and opportunities for

SD. The preliminary version of the scale was tested on 450 individuals in the San Francisco area who were with and without disabilities, aged between 6-25. There was a varied racial distribution, and a high number of children (80%) from low SES families. Split-half reliability was at 95% and test-retest reliability at 74%. Males and females did not have significantly different scores, nor did one race-group score significantly different from another. Children with low SES scored lower than other children, as did those enrolled in special education programs.

Given that the cognitive ability and adaptive behavioral symptomology of FASD varies widely between cases (Bredberg, 2011; Duquette & Orders, 2010), the establishment of measurement equivalence is critical. The AIR SD scales have been shown to maintain validity across multiple ability groups (Shogren et al., 2007). Overall, this measure was highly suitable for the current study.

Procedure

Ethical clearance was obtained from the McGill University research ethics board as well as the Toronto District School Board to contact the educators involved and to facilitate the implementation of the recommendations that will come from the study. Most of the participants were recruited from areas in Ontario that are located outside of Toronto; as such, each participants' school board was contacted. These school boards did not have official research ethics boards and thus permission for contact with the child's primary educator and entry to the school was obtained through communication with the principals of the schools.

Children aged 10-15 previously diagnosed with a disorder falling under the umbrella term of FASD (FAS, pFAS, ARND) were recruited from various organizations and community outlets in Toronto, Ontario, and its surrounding communities. Specifically, coordinators of FASworld, FASone, FASlink, as well as the administrator of a Canadian social media group targeted toward advocacy and adapting environments for children who have a FASD, circulated the flyer (Appendix A) to their listserv's and if possible, posted it online. Additionally, the flyer was posted in the FASD diagnostic clinic at SickKids Hospital in Toronto, Ontario. The flyer was re-circulated by FASlink, FASworld, and the social media group approximately 12 months after the initial circulation to boost recruitment. Compensation in the form of $25 cash was provided to the child participant's guardian.

A criteria-based sampling method was employed. Participants were excluded if the child was institutionalized or home-schooled, or if they were diagnosed with severe behavioral disturbances or comorbid pervasive developmental disorders such as ASD. These exclusionary criteria were assessed upon first contact with the guardian (using guardian report) and before setting up the first meeting with the child. Based on these criteria, two participants were declined because they were home-schooled due to severe behavioral concerns. Recruitment timing was influenced by the length of time the teacher had known the child participant. Though it was not an exclusionary criterion, effort was made for participants' parents to name teachers who had known the child for a minimum of six months, therefore the timing of data collection was generally reserved to between February and June, unless the teacher or special education teacher had worked with the child participant the year prior to data collection.

In all cases, I conducted a phone interview with the guardian of the child to explain the study, explain consent, offer opportunity for the guardian to pose questions regarding the study, and obtain email addresses to send the consent forms. At this point, the guardians shared the name of their child's school and their main educator. I contacted the child's school to obtain the principal's permission to enter the school and work with the participant. I also contacted the child's main educator to gain their consent to ask them to fill in the questionnaires. Of note, one guardian declined to have her child's school/teacher participate in the study. Consent forms and the assent form used for the child participants can be viewed in Appendix B.

Once I met the child participant and procured assent, a 20-40-minute session took place. The sessions occurred at the participant's school in seven of eight cases; one session took place in the participant's house due to a lack of school involvement. In this case, the guardian filled in her questionnaires while the child participant took photographs and spent time with me. The remaining children completed the questionnaires and took their photographs and explained them at school. The child's main educator either filled out the questionnaires during this time or was given a self-addressed, stamped envelope to return the questionnaires to me. Guardians also filled out the questionnaires at the school, except in one case where it was most convenient for the guardian to fill out the questionnaires at her home after the school sessions had taken place.

During the sessions, I explained the task and asked the child to brainstorm ideas of what they would like to take pictures of. A previous study using photo-taking with youth recommended that directions be worded generally to foster creativity, yet be structured as though they are completing a specific mission so that the children have some guidance (Strack et al., 2004). In each of the school-based sessions, I was asked by school staff to accompany the participant while they took photos. The child participant in the one home-based session had gathered several items from her room and backpack in preparation for our meeting. The items were related to what she felt successful at when at school, and what she found challenging.

The children took the photographs with an Apple iPhone 4. The smartphone had been restored to factory settings (i.e., wiped clear of any information or settings put in place by the previous owner) and the SIM card had been removed prior to its use for this study. Each of the children were familiar with how to use the device to take photographs; none required any teaching or training. When the children had finished taking their photographs, I uploaded them to my laptop to provide a larger view of their work. The participants were asked to select two photographs that they felt were the most significant regarding what they felt were their most successful and most challenging aspects of their school day (one photograph for each successful and challenging aspect).

A discussion then took place as to why they chose those pictures and what they meant to the child. The discussion was guided by SHOWeD, an acronym representing: What do you *See* here? What's really *Happening* here? How does this relate to *Our* lives? *Why* does this problem, concern, or strength exist? What can we *Do* about it? Multiple studies have successfully used SHOWeD to elicit dialogue from photograph data (Brazg et al., 2011; Peterson et al., 2010; Stephenson, 2012; Strack et al., 2004; Wang et al., 2000; Wang et al., 2004; Wang & Pies, 2004). The child participants' responses were immediately typed verbatim into a word processing document on my laptop. I read the responses back to the children to ensure I had captured their responses correctly. I made all efforts to maintain the integrity of the child's perspective throughout the encounters.

Participants

Eight child participants aged 10-15 were recruited from southern Ontario over the course of two years. Please refer to Appendix C for demographic information. Please note race and ethnicity of the participants was not asked out of respect for communities who have been historically singled out as having high FASD prevalence rates. I wished to detach from these isolating and stigmatizing stereotypes experienced by people with FASD and given that this is not a population-level study it was deemed appropriate to honor the participants' privacy rather than use the information in the analysis. There were three sets of siblings within the data set; one participant had no siblings. In all cases, there were no other children being raised in the home at the time of data collection, other than the siblings identified. As mentioned, pseudonyms are used for all participants.

Data Analysis

As a novice researcher, I required structure and guidance to analyze the data. Thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2014) was used to understand participants' photographs, narratives, open-ended question responses, and questionnaire scores. To foster the most representative and ecologically valid interpretation of the child's experiences from the data, triangulation occurred through constant comparison. That is, I asked the child outright if my interpretations were correct, attempting not to query the child in a leading manner. Further verification occurred through multi-modal data collection. Specifically, the child's experience regarding SD was represented by their photographs, their narratives regarding the photos, as well as three questionnaires directly tapping elements related to SD. Parent questionnaires and in seven of eight cases, teacher questionnaires tapping the child's perceived ability and opportunity for SD, their adaptive behavior in each respondent's environment, and their QoL at home was also used to triangulate data obtained from the children.

The data analysis took place in multiple stages. There are several guidelines for thematic analysis; those outlined by Braun and Clarke (2006) and Clarke and Braun (2014) were utilized in the current study. There are several advantages to using this system. For one, the steps involved allowed my analysis to stay true to the tradition of descriptive phenomenological research as they mirror the methods outlined by phenomenological research scholars (e.g., Giorgi & Giorgi, 2008) while also providing increased structure to the analysis. The structure helped me as a novice researcher and allowed for both complex and cursory level descriptions of the data set, aiding to expose the similarities and differences within the data. Especially important for the purposes of the current study, this method of analysis allows for psychological and social interpretation and can thus be useful in advising policy development and practical recommendations for caregivers, educators, and school psychologists.

Specifically, the first step was to familiarize myself with the data. It was in that process where I obtained an overall sense of the data set. I immersed myself in the data by reviewing the photographs, reviewing the brief narratives, scoring and reviewing the questionnaire responses, and organizing and reviewing the responses to open-ended questions on the questionnaires. The questionnaire data were scored as per each measure's prescribed methods. Comprehensive notes were taken throughout this process to refer to in later steps of the analysis.

Regarding the ABAS-2, scoring was completed through the ABAS-2 computer scoring assistant, a licensed software available through the questionnaire's distribution company. Standard scores for the composites and scaled scores for the individual domains were calculated, as well as their respective percentile ranks as per a normal distribution curve. Composites and domains that were stronger or weaker than the individual's predicted performance based on their overall scores at a statistically significant ($p = 0.05$) level were provided by the computer scoring system.

The AIR self-report, guardian, and teacher questionnaires each resulted in an overall SD score. The overall score was comprised of questions regarding the child's capacity and opportunity for SD. The total possible score for a self-report was 120, 90 for a guardian, and 150 for a teacher. The maximum capacity and opportunity composite scores for a self-report were 60 each; for teacher and guardians the maximums for capacity and opportunity were 30 and 60, and

90 and 60, respectively. For ease of comparison, the obtained total, capacity, and opportunity scores were converted into percentages of the maximum possible score for each category.

The KINDL-R was comprised of 24 questions under six domains. Each item was given a value of 1-5 by the respondent. The total was transformed to create a value ranging from 0 to 100.

The next phase consisted of an initial coding process wherein I identified representative extracts from the data, and gave them each a code. The extracts were representative of basic elements of a feature or characteristic of the data. It was important to avoid sacrificing too much of the context of the data extracts in the coding process to maintain the integrity of the information; thus, photograph content was analyzed for objective information as well as contextual information. The same process was applied to the brief narratives and the open-ended question responses. For the numerical questionnaire data, the scores of the subtests within each measure as well as the total scores of each measure were compared within and between respondents to investigate what codes could be made from this information.

In the third phase (identifying themes), broader themes were derived from the codes. The data extracts combined and diverged into overarching themes. I took notes of my ideas about the relationships across different themes and levels of themes. I then made thematic maps using cue cards to organize and structure the data.

The fourth phase consisted of reviewing and refining the themes. I ensured that themes did not overlap and that each theme had sufficient data to support it. Themes with too much information were separated into different themes. The refined themes were then considered within the context of the entire data set. This reflective process was necessary to ensure the validity of the themes and of the relationship between the themes. Further refinement of themes and thematic maps were made to ascertain a representative presentation of the overall data.

Defining the themes and naming themes appropriately encompassed the fifth stage. A clear definition of the themes and theme names accurately portrayed the “essence” of the data extracts within their respective themes. The relationship between the themes was also important to consider in creating the definitions and names.

The final step of analysis was the production of the report of the analysis within the results section of this dissertation. Overall, the goal of this stage was to communicate the main findings using examples from the data. The findings were also framed within the context of the research questions.

Validity Procedures

Information power was assessed using a 5-point system as a guide (Malterud, Siersma, & Guassora, 2015). Malterud and colleagues describe how a study’s aim (narrow versus broad), specificity of topic (dense versus sparse), theory (applied in framework versus none), quality of dialogue (strong versus weak) and analysis approach (case-by-case versus cross-case) influence the number of participants required to garner enough information to create a viable, sound, argument. The current study’s narrow aim was to explore child participants’ experiences at school regarding the development of SD skills. The child participants were specifically required to have been diagnosed with FASD and to be educated within an inclusive classroom. The study was guided by the PPCT model (Bronfenbrenner & Morris, 2006) to frame the understanding of the participants’ experiences. Each child’s experiences were analyzed in-depth through multiple modes of data, as well as cross-analyzed to begin to explore trends. Data were strong in the sense that each child participant and the adults involved could share their views through at minimum questionnaire data; further opportunities for elaboration were offered through open-ended questions on the questionnaire forms. Child participants were also able to express themselves through photography and dialogue about the photography. Through constant comparison of data throughout the course of the study, I determined that the data were sufficient for the study.

Several methods were used regarding validity. Triangulation between the multiple sources of data worked to increase the level of validity of the themes. Opposing ideas and other interpretation of the data are also offered in the discussion section. As much as possible, my biases were acknowledged throughout data collection and analysis. Trustworthiness of the photograph and interview data were obtained through constant verification during the discussion with the child participants about the photographs.

PPCT model in the current study. In the current study under the PPCT model, several variables were targeted. As an exploratory study, the variables were parts of a whole--that is, the study was an attempt to produce a fulsome story of eight children diagnosed with FASD's experiences at home and school as they relate to their developing SD skills.

Process. The proximal processes were explored first through describing the children's photographs and their brief narratives. These sources provided information on what processes were foremost on the children's minds. Further information on proximal processes was gained through analysis of self and proxy reports of the children's SD and QoL, as well as reports of their goals and progression toward goal completion. The self-report data were compared to proxy report data to gain an understanding of any processes that may be occurring between the children's interactions with the parents and guardians. Their goals and reported progression toward their goals were key sources of information regarding what types of proximal processes may be occurring in their home and school environments.

Person. Within the current study, the children's adaptive behavior as assessed by their guardian as well as their teacher provided information regarding the children's personal characteristics that might be influencing their environments, including their skills in interacting with adults, peers, the community, and with engaging in leisure time. Reports of the children's goals and progression toward goal completion, as well as information from SD and QoL questionnaires were also used to understand the children's individual characteristics that might be influencing their SD.

Context. Environmental influences were explored through the guardian and teacher's questionnaire responses; how their perceptions could influence the children's SD were considered in the analysis of the data. Mesosystem influences were explored through the adults' questionnaire responses regarding the guardian's thoughts about and interactions with school, and the teacher's thoughts about and interactions with the child's home environment. The children's photographs, brief narratives, and self-reports also provided information on their micro- and mesosystemic influences; their experiences revealed how they interacted with peers, teachers, and families. The children also shared a wealth of information regarding their school environment. The literature review and analysis offered information to situate the data within the exo- and macrosystemic levels.

Time. The time-related factors are important to consider in many situations, though within the current study, it was not possible to consistently identify timeframes and frequency of the processes impacting the child participant's SD. Chronosystem influences were considered when situating the findings in the current socio-political context. Historical information was also reflected upon.

Summary

This section provided a philosophical rationale for using qualitative research to explore the complex and nuanced topic of SD in children with FASD within a PPCT framework. The processes that may influence the children's SD were investigated through photographs and brief narratives originating from the children themselves, open-ended questionnaire responses regarding the child's goals and goal-setting behavior from all participants, and self and proxy reports of SD and QoL.

Information regarding the children's personal characteristics that could impact their SD was garnered through means of the adaptive behavior measure. Supplementary information regarding their personal characteristics was obtained through self and proxy measures of SD and QoL, as well as through the identification of how well the children were doing at meeting their goals.

Contextual data were gathered through self, guardian, and teacher perspectives of elements of the children's microsystem (e.g., QoL data, skills related to adaptive behavior, capacity and opportunity for SD). Mesosystemic influences were gleaned from teacher and guardian questionnaires about how the adults viewed the setting that they were not directly responsible for. For example, the teachers responded to questions regarding their perceptions of the children's SD at home, and the guardians did the same for the children's SD at school. Broader-scale influences at the exo-, macro-, and chronosystem levels were considered in the review and analysis of the literature, and were reflected upon during the analysis of the data and in positioning the findings within context. Chronosystemic influences were considered in the analysis of the data and in situating the findings in context.

Descriptive phenomenology was chosen as the qualitative research tradition as I described the data concretely first, and only derived meaning from the data after full submersion in the data while actively attempting to reduce my own bias and interpretation to highlight the participants' voices. A description of the types of data collected was provided, and the procedure of the study was defined. Participant information was specified. The data analysis process was described, as were the validity procedures. The next section will include the child participants' profiles and the outcomes of the analysis of data including the identification of overarching themes.

Results

The current study sought to investigate children diagnosed with FASD's perspectives and experiences as they pertain to their SD. This information will aid in the development of targeted interventions for the FASD population for schools and parents regarding building children's ability to cultivate more self-determined behaviors. Further, the children's voices have not been historically given space in the literature; this study allowed the children to share their opinions and experiences in a more formal academic setting. The child participants were asked to take photographs of what they found the most challenging and what they felt the most successful at in school. They also shared their thoughts regarding their photographs in the form of semi-structured interviews following the SHOWeD method. In addition, the child participants completed questionnaires regarding their SD and QoL. Their guardians completed the parent versions of these same questionnaires as well as a standardized measure of adaptive behavior. Further, the teacher most involved in each child participants' education completed the SD measure and the adaptive behavior measure. As part of completing the SD measure, respondents were asked to identify one or more of the child participants' goals and the child's progression toward reaching them.

Each child participant's profile is presented below. Their profiles include information from their photographs, SHOWeD responses, goals, and questionnaire data regarding their adaptive behavior, QoL, and SD. Themes from the group are then presented, first regarding the photographs and their narratives, the questionnaire findings including goal identification, and then the more over-arching themes conclude the section. For a general overview of the questionnaire results along with descriptive statistics, please refer to Appendix D. Broad explanations of the ABAS-2 subdomains are found in Appendix E.

In interpreting the children's profiles, it will be necessary to understand the parameters of the adaptive behavior scores from the ABAS-2, the SD scores from the AIR, and the QoL ratings from the KINDL-R. The results from the ABAS-2 are reported as standard or scaled scores and standard qualitative descriptors. According to the ABAS-2 manual, there are seven qualitative descriptor categories under which scores are sorted (Harrison & Oakland, 2008). They include: extremely low (</= 70 standard score, </= 3 scaled score); borderline (71-79 standard score, 4-5 scaled score); below average (80-89 standard score, 6-7 scaled score); average (90-109 standard score, 8-12 scaled score); above average (110-119 standard score, 13-14 scaled score); superior (120-129 standard score, 15 scaled score); and very superior (=/>130 standard score, =/>16 scaled score). These descriptors allow a reader to better understand and compare how the child participants' strengths and weaknesses in adaptive behavior may appear to observers within a typical home or classroom.

AIR questionnaire results are reported as percentages. As mentioned in the methods section, the AIR's total SD, capacity, and opportunity scores were calculated as percentages of the total number possible for that category depending on the format of the questionnaire. KINDL-R questionnaire total and sub-domain results are reported as scores out of 100.

Participant Vignettes

Summer. Participant 1 (Summer, age 12) was the sole participant without another sibling in the study. She was adopted by her foster parents. Summer was a pensive and reserved young girl who had clear pride in her accomplishments. She thought carefully about each of her responses on questionnaires and during her conversation with the researcher regarding her photographs. Please refer to Figure 1F and Figure 2F in Appendix F to view Summer's photographic depictions of what she felt she was most successful at and what she found the most challenging at school.

Her successful photograph demonstrated her passion for art in many forms. Summer's favorite animal, the bald eagle, is portrayed both as a sculpture and as a painting. She sewed a panda bear pillow. Of most note was her hand-drawn self-portrait in which she appears despondent, sad, and confused. In discussing what she found she was most successful at in school, while she chose art overall, she mentioned mathematics to the researcher as another area in which she is successful. To consider mathematics as one of her most successful areas at school was in stark contrast to many of the other participants of the current study who chose mathematics as the most challenging aspect of their school day (i.e., 50% of the total sample).

Summer's narrative regarding her successful photograph revealed that she enjoys drawing and completing art projects at home and at school. She felt that the strength she has in art is innate. She stated that she is, “just good at it” when asked why she has this strength. When asked what can be done to help support her strength, she stated, “more art classes!”

Summer’s challenging photograph showed her aversion to writing assignments. She photographed what appeared to be a creative writing assignment in which she took on a narrative role of a rabbit visiting its grandmother. She found it difficult to articulate her challenges in written work. She shared that, “writing is really hard, it takes forever”, but that she can ask for help from her mother if she requires it.

Summer’s ABAS-2 scores as completed by her guardian indicated that overall, Summer is functioning within the extremely low range. Her strongest area of competence was within the social realm, followed closely by leisure skills, each falling within the average range though her social domain score was significantly stronger than would be expected given her overall profile. Indeed, her social composite score was the highest of the group of participants. Her self-direction and self-care skills were significantly weaker than the rest of her profile, rated within the extremely low range, though several other domains were also within the extremely low range (i.e., community use, home living, and health and safety).

On the AIR SD measure, her overall score was high according to both Summer and her mother. She reported that her own capacity for SD is higher than her opportunity, opposite of what her mother reported. Summer and her mother’s rating of her overall opportunity was similar; her mother rated Summer’s home setting as higher for SD opportunity than at school, while Summer reported similar opportunities for SD in both settings.

Regarding goal setting, Summer shared that she wished to keep her spelling and mathematics grades up at 100%, which was roughly consistent with one of the two goals her mother had indicated Summer was working on (i.e., keep receiving A’s or A+’s in mathematics).

Her mother also identified that Summer was working toward competing in a dance competition. Summer felt that she was on track to achieving her goals, though her mother reported that Summer requires prompts and reminders to be able to, "completely follow through" on goals.

Summer's QoL responses were overall quite low, even when taking into consideration that she had been sick the last two weeks and the physical QoL subdomain was likely artificially lower than her norm as a result. The questionnaire scores revealed that she perceived herself to have poor self-esteem--her score on this subdomain was a zero. Additionally, individual item responses showed that she was worried about school, she found school difficult, that she did not have fun, and that she often felt alone and bored. Socially, she reported that she got along with friends "all of the time", though also endorsed that she only "sometimes" played with them. She "sometimes" feels different from others. When these results are compared to her guardian's responses, we see that her guardian may not be aware of her difficulties. While Summer rated herself 31, zero, and 13 on emotional well-being, self-esteem, and school life, respectively, her mother scored her at 75, 63, and 50 on the same subdomains.

In summary, Summer's story is one of a social child whose academic efforts appear to vary from ardent to labored. As she appears to be stronger socially, she likely receives corrective attention and feedback regularly and meaningfully from adults regarding non-social domains such as academics. Perhaps this feedback tends to also be focused on observable and/or measurable outcomes. Thus, Summer appears to focus on academic progress. For example, Summer identified an academic goal (achieving high grades in mathematics and spelling). As she was rated by her mother to have low average functional academics and was reported to be receiving A's and A+'s in mathematics, it is possible that she was experiencing successes in some areas at school and is looking to continue these successes. She also mentioned during her narratives regarding her photographs that while it was not her very most successful area at school, she felt did feel successful in mathematics. Indeed, her mother also identified that one of Summer's main goals was to keep her mathematics grades up.

Moreover, she felt strong in her ability to create art as demonstrated by her photograph of success at school. Summer's mother also identified that Summer is working toward improving her dance skills as a goal. Summer and her mother generally agreed that she has high SD and that she is receiving opportunities to practice SD, especially at home. She was also reported to have average social skills on the ABAS-2 and high self-reported social QoL. However, upon closer inspection of the QoL items, Summer is experiencing some social concerns as well. Additional review of the successful photograph revealed that she appeared confused, sad, and despondent in her hand-drawn self-portrait. On the QoL measure, her self-reported self-esteem was the lowest of the group at zero, which together with the self-portrait suggests significant emotional distress. Additionally, Summer's self-reported QoL at school was low, and she chose to photograph an academic subject (writing) as the most challenging aspect of her schooling.

Overall for Summer, at school, the focus from others tended to be on her weaknesses. She appeared to be feeling the effects of this focus, as demonstrated by low self-esteem. Summer's perceived social and artistic strengths and interests were recognized by her mother and appeared to be integrated into her extracurricular activities (i.e., dancing).

Participants 2(Adam), 3(Mack), and 4(Chris) were born of the same mother and were being raised by their biological grandmother. It was reported that it was unknown if the boys are full or half-brothers. Their biological grandmother reported that the boys' mother had been diagnosed with FASD.

Adam. Adam (age 11) presented as a joyful and happy-go-lucky young boy. He responded positively to having one-on-one attention. It was difficult for the researcher to elicit what Adam found challenging at school due to his optimistic attitude. Adam appeared to take pride in having mastered the school's hallway layout. Adam's chosen photographs are seen in Figure 3F and Figure 4F in Appendix F.

His successful photograph depicted hockey helmets kept in his school gymnasium's storage room. He reported feeling happy when playing sports, thus he and the researcher took to exploring the gymnasium for him to find the materials that best represented when he felt his most successful. Adam lit up while in the gymnasium and regaled the researcher with a story about how he had scored a goal in one of his recent physical education classes. Regarding his SHOWeD responses, he indicated that at the time he thought he was skilled at hockey because he was fast. He stated he would like more hockey time in school.

Adam was one of the four participants who chose mathematics as his largest challenge at school. He drew a simple mathematics equation on the chalkboard in the room where he and the researcher were meeting. He shared that he hates math and that it makes him "feel bad." He felt as though despite his efforts, math was "still hard."

Adam's guardian and teacher ABAS-2 responses indicated that Adam was functioning overall within the low average range at home, and within the extremely low range at school. His reported strength in both settings was community use; additionally, at home his communication and health and safety skills were significantly strong. Self-direction was a consistent weakness across settings. He was also weak in the social and self-care domains at home and in functional academics at school.

Adam’s total SD score on the AIR varied according to the respondent; specifically, his guardian’s rating was the highest, followed by his own impression of his SD. Adam’s teacher rated him the lowest in total SD; in fact, Adam’s teacher’s score was the lowest in the overall group of all participants. Adam rated himself as having a higher level of capacity for SD than his proxy reporters, but all respondents agreed that his opportunity for SD was greater than his capacity. His teacher felt that Adam had much more opportunity for SD at school than at home; his guardian’s responses tended toward that direction as well though to a significantly lesser degree. Adam’s scores revealed that he felt there were fewer opportunities for SD at school than at his home, typical of the overall child participant group.

Adam shared that his goal was to be a police officer when he was older. This goal was in line with what his grandmother reported as one of his goals. She additionally reported Adam to have a goal of being a “rock star.” They each felt he is moving positively toward these goals; both he and his grandmother indicated that he is participating in activities related to goal-achievement based on what is known about a police officer’s role, but the activities did not represent what would realistically help Adam achieve that goal. For example, Adam indicated he is practicing his aim with paintball guns, and his grandmother shared that Adam is watching “cop shows” in preparation for his career choice. Adam’s teacher indicated that his goal at school was “organizing his desk.” His teacher had just begun implementing a color and binder system that Adam was responsible for to aid in achieving the goal. The teacher reported that Adam had so far been successful at maintaining the binder and color system and keeping his desk organized.

While Adam and his guardian’s total KINDL-R scores were close in value, they differed considerably regarding almost all subdomains of the measure. Specifically, Adam felt his emotional QoL was high as compared to what his grandmother reported. He also scored himself higher on family and social life. Adam's guardian felt that Adam's self-esteem and school life were higher than how Adam himself perceives these areas of his life. Thus, Adam and his grandmother generally disagreed with regards to their perceptions of his QoL. Further, Adam's self-reported score for school life and his guardian's scores for family and social life were appreciably lower than those of the average of the group, beyond the range of the standard deviation.

In summary, Adam's results suggested he is an active child who enjoys and feels successful in sports. He appeared to have a positive outlook as well. He had difficulty with academics; mathematics and organization were identified as areas of weakness. Adam's goal of organization (as reported by his teacher) is consistent with Adam's weak self-direction and functional academics. Organization of materials is generally an area of difficulty for individuals who have challenges with executive functioning, a skill required for self-direction. Additionally, his self-reported and guardian-reported career goal of becoming a police officer also reflected his overall profile of being a personable, active boy who enjoys hands-on tasks as opposed to academics. However, the goal is quite far in the future and the strategies Adam and his grandmother described lack exploration of other, more realistically helpful options that would be more reflective of his strengths while also taking into consideration his needs.

Moreover, Adam's QoL was rated as considerably low for school life (self-reported) and in the family and social life realms (proxy report). These areas of weakness are consistent with those identified on the ABAS-2 (i.e., functional academics, social, self-care, and self-direction). Given that he was more objectively weak in social skills than he perceived himself to be at the time of the current study, it is likely that more social difficulties will develop as he ages and potentially becomes increasingly isolated from his peers.

Mack. Mack (age 12) appeared withdrawn and over-tired. He spoke in quick, short, bursts and avoided eye contact. He had a more negative demeanor compared to his brother, Adam, except when speaking about his favorite subject (science). Mack spontaneously reported that he used an iPad in class and that it helped him keep busy. He shared that sometimes he tried to play games on the iPad instead of working. Please see Figure 5F and Figure 6F in Appendix F for his photographs.

He chose to photograph science experiment equipment for his successful photograph, and chose a mathematics worksheet to represent his largest challenge at school. Mack's science experiment photograph showed short and tall plastic beakers strewn about a tall science laboratory table. A two-liter pop bottle and several different cooking oil containers were seen in the background, as well as a large amount of paper napkins placed near the beakers, suggesting the experiment involved showing the students a potentially messy situation. Brightly colored markers were in the foreground, a short point-form list of instructions appeared to be written on the blackboard on the wall behind the table. The contents of the photograph together suggested that the experiment the students conducted had clear instructions and was highly engaging, fast-moving, and hands-on. The in-class experiment displayed a marked departure from the more traditional, didactic style of teaching a concept.

In his narrative, Mack shared that the photo showed him "learning about science." He stated that he likes science and that he thinks science is "cool." He did not know what could be done to increase his exposure to or involvement with science.

Mack photographed a mathematics worksheet to exemplify his struggles with mathematics. It was a grade five lesson on patterning and algebra in which Mack was to find the rule of a growing pattern. The worksheet appeared to be from an extra-curricular mathematics textbook (Jump Math) that teachers in Ontario typically use as a resource to supplement the curriculum textbooks or for students who require extra practice. The worksheet showed that Mack was working on mathematics concepts from approximately 1.5 grades behind his grade seven level. His printing on the worksheet appeared belabored and uneven, potentially indicative of fine motor skill difficulties. One of his two responses on the sheet is correct, the other is not. He discussed that he does not understand math "at all" and that it is "too hard" for him. He felt that he should "keep studying" to address his challenges in math.

Mack's guardian and teacher ABAS-2 responses indicated that Mack was functioning overall within the low average range at home, and within the extremely low range at school. Both his grandmother and his teacher rated him at the lowest limit of the average range on the social composite. His reported strength in both settings was community use; additionally, at school he had strengths in social and leisure skills. At home, his health and safety skills were significantly strong. Self-care was a consistent weakness across settings. He was also weak in the self-direction domain at home and in communication at school.

Mack's total SD scores on the AIR were consistent between respondents. Specifically, his own impression of his SD was highest, followed closely by his teacher's and then his guardian's ratings. Mack rated himself as having a higher level of capacity for SD than his proxy reporters with all respondents agreeing that his opportunity for SD was greater than his capacity. Mack, his teacher, and his guardian's responses showed generally consistent opportunity across both home and school settings.

Mack's self-identified goal was to "get better at reading." He was using an application on his school-funded iPad to help him learn basic reading skills and shared that he feels like his skills are improving. His guardian identified that Mack's goal was to be a firefighter. She reported that Mack was working toward this goal in a way that was related to a common perception of a firefighter's role, though not necessarily helpful in increasing his skill level. She stated that Mack was "too young to start" knowing if he was achieving his goal. Mack's teacher identified that Mack was working toward finding "a pattern rule when given a table of values" in mathematics. He was reported to be doing well in achieving his goal; Mack was participating in guided practice, group math activities, and was independently seeking iPad applications for skill building.

Mack's KINDL-R scores showed that he sees himself as having a strong QoL regarding his physical health and his school life. His grandmother's scores were also high for Mack's physical QoL, though were lower for his school life. His social life scores were low according to both himself and his grandmother. His guardian reported a much higher emotional QoL for Mack than Mack did for himself, though the trend was reversed for self-esteem and the disparity was to a lesser degree.

Overall, Mack's profile suggested a curious and reserved child who appeared to enjoy school. He is the only child participant who chose an academic subject to document as a successful photograph. Further, his self-reported QoL was high for school life, and he indicated that his goal at the time was to improve his reading skills. His teacher also reported an academic skill as his goal, and both Mack and his teacher reported that Mack was moving positively toward goal achievement. Moreover, in his challenging photograph narrative, Mack discussed how he felt inclined to continue working on mathematics despite having low self-efficacy in the area.

In contrast, his grandmother, like what she identified for Adam (Mack's brother), identified a career goal for Mack and cited activities related to common perceptions of what that career entails rather than what would realistically move Mack toward achieving that career. Additionally, despite having relatively strong social skills as measured by the ABAS-2 in both home and school settings, Mack and his grandmother reported his QoL with respect to social life to be low. Therefore, it appears that Mack lacks the ability to follow-through and use his social skills effectively and meaningfully. This is perhaps due to weaknesses in self-direction, communication, and SD skills regarding being able to identify and plan goals. It is also possible that Mack is eager to please the adults in his life and usually follows through on directions from others; this tendency could artificially inflate his social adaptive skill scores. Mack may not be able to organize himself to please both himself and others, so may often choose to do to what he feels the adults in his life want from him. Another factor may be that the social demands are different for peers--they may see him as different and respond accordingly as might be expected given their developmental level.

Chris. Chris (age 14) was an energetic and friendly young man with a sense of humor. He was quick to respond to questions and became somewhat impatient when encountering questions that he did not fully understand. He was eager to show the researcher around his school; he became visibly delighted when he learned he would be allowed into the gymnasium with special permission to take his successful photograph. Chris, while capable of communicating verbally, appeared to rely heavily on non-verbal gestures to accentuate the meaning of his words (e.g., nodding vigorously, using hands to demarcate how much or little he liked an activity). Chris' photographs can be viewed as Figure 7F and Figure 8F in Appendix F.

Chris' perspective in his successful photo was from the corner of the gymnasium and from slightly below eye-level. It is a blurry photograph, indicating a hurried approach to taking the photograph. As a viewer, it appeared as though despite Chris' joy about having special access to the gymnasium, he felt uncomfortable being there and did not wish to prolong his time there. The photograph itself showed badminton and basketball nets; he shared that he had wished to take a photo of sports in general. In his SHOWeD responses, he revealed that he chose the gymnasium because he felt sports are "fun" and that he is "really good at playing sports." He thought that he should "keep going to gym class" to continue to build his strengths in the area.

Again, in the challenging photo, Chris' chosen perspective was from the front corner of a room and from slightly below eye-level. In this case, the room was his geography classroom. A United Nations flag is the focus of the photo; it sits in the top-center of a bulletin board. A map of Southern Ontario and a map of Northern Ontario boarder the flag. The bulletin board is also home to a map of Canada, a map of the world, and several smaller posters that appear to be a mix of travel advertisements for different areas of Ontario. A historic Royal Canadian Air Force flag dons the wall to the right, pale blue in color with a Union Jack in one top corner and an encircled maple leaf to its diagonal. Two old-fashioned telephones sit on a shelf below the bulletin board. Compact disks and other classroom materials share the shelf with the old telephones. Each item appears to have its own place on the shelf. The students' empty wooden desks are organized neatly into three rows of two, with identical vibrant blue chairs tucked in behind them. The color of the chairs highlights the blue of the United Nations and Air Force flags, as well as the blue of the water of the maps behind the chairs. The room exudes order.

He stated that his geography class was "the worst class" and that he hated it. He reported "nothing happens here except boring stuff" and that he had to do the homework "even if it's hard." He did not feel there was anything he could do about the situation to improve it.

Chris' overall adaptive behavior was reported to be extremely low in both home and school settings. His reported strength in both settings was leisure; additionally, at home he had strengths in communication and community use. Self-direction was identified as a weakness across settings. He was also weak in the social domain at home.

Chris rated himself higher in overall SD than did his teacher and grandmother. He also perceived himself to have a higher capacity and opportunity for SD as compared to what his proxy respondents reported. Chris' guardian rated him as the lowest of the overall group of participants in capacity for SD. His teacher's rating of his opportunity for SD was also the lowest of the group.

Regarding goal setting, Chris identified that he wished to earn money for lunch or for a new videogame. He was planning to shovel driveways for money, though stated that he was not doing well in achieving his goal. His guardian shared that she felt that Chris did not have any goals. Chris' teacher identified that Chris' goal was to manage his own behavior. She listed several specific strategies that Chris and the school staff have been trying to help Chris achieve this goal. The teacher wrote that there have been "baby steps" in achieving this goal, though she felt that Chris did not learn from his mistakes.

Chris' QoL results revealed a great discrepancy between how Chris perceives his own QoL and how his grandmother reported it. Chris' self-report scores did not stand out from the group. Conversely, his grandmother rated him as the lowest in the group in four of the six domains (i.e., emotional, self-esteem, family, social). Chris and his grandmother reported similar levels of QoL in the areas of Chris' physical health and school life.

Overall, Chris' guardian and teacher observed him to be struggling in several areas including academics, socialization with adults and peers, behavioral regulation, and goal setting. For example, Chris' overall SD, QoL, and ABAS-2 scores were quite low and in many subdomains of the measures, his scores are the lowest of the overall group. Conversely, Chris' self-reported SD and QoL are significantly higher. His grandmother reported that he had no goals, and his teacher reported that his goal was to manage his behavior. In Chris' self-reported goal of earning money by shoveling driveways, he provided a more immediate, defined, and attainable goal than what his proxy respondents reported. However, he felt that he was not doing well in achieving his goal. Given his ABAS-2 scores in self-direction, Chris clearly would require support in organizing himself for tasks. It is unclear if he was receiving the type of support he would need to be able to follow through on shoveling driveways.

Perhaps Chris feels he is functioning well and is not fully aware of his difficulties. Alternatively, he may be in the habit of portraying his skills and capabilities in a more positive light; he could be counteracting negative feedback he receives regarding his behavior, social skills, and academics to maintain pride in himself. Chris, one of the oldest child participants of the group with potentially the most experience with new adults, may have also been answering with the bias of social desirability.

Participants 5 (Ethan) and 6 (Alex) are biological brothers (it is unknown if they are full or half-brothers) who are being raised by adoptive parents. Ethan (age 10) made a strong first impression. He was happy to be part of the study and jumped excitedly when he entered the resource room where the researcher and Ethan's special education teacher were seated. He required a few minutes to settle into the space and get oriented to what participation in the study would entail. He was curious, asking several questions regarding the details of the assent script. Please refer to Figure 9F and Figure 10F in Appendix F for Ethan's photographs.

Ethan. For his successful photo, Ethan asked the researcher if he could draw something he could then photograph. He was provided with colors, paper, and a pencil. Ethan drew a quick, simple picture of a schoolyard scenario. Five stick-figures are shown facing each other, three facing right and two facing left. Two of the right-facing figures are huddled together, frowning. The third is holding a ball under one arm and making a fist with the other hand. There is a speech bubble coming from this character demanding one or both left-facing figures to "go away." On the other side of the page, the first left-facing figure is responding in its speech bubble "bie" (i.e., "bye"). The second left-facing figure states "come play with us." Ethan shared that he was the character saying "bie" in his drawing, and that he was proud of himself for his conduct in a similar, real-life situation where he calmly walked away from people who did not want him to play with them. He shared in the SHOWeD responses that he feels it is not fair when others do not let him play with them so now he walks away and finds someone else to play with. He attributes his new skill to his mother and the special education teacher helping him to learn to walk away when he is angry. Ethan felt that he would continue to walk away if he is angry in the future.

Ethan was one of the four participants who chose to photograph mathematics as their challenging photo. Here, Ethan's photograph was of a photocopied worksheet teaching division with whole numbers wherein a four-digit number was divided by a one-digit number in two different ways. The practice problems were not yet completed. The work was approximately at grade-level. To quote Ethan, "long division is hard because I just don't get how to divide the bigger number and there are too many steps." He stated that this problem existed "because my brain works differently." In the interest of improving his ability to complete long division problems, Ethan felt that he should do his homework and ask for help if he is having trouble.

Ethan's overall adaptive behavior was reported to be extremely low at home and at school. His reported strength in both settings was leisure; additionally, at school he had strengths in social, community use, and self-care skills. At home, his health and safety skills were significantly strong. Self-direction was a consistent weakness across settings. He was also weak in the self-care domain at home and in functional academics, school living, and health and safety at school.

His total SD was relatively consistent across all three respondents, though Ethan's appraisal of his own SD was the highest. Ethan's parent and teacher rated his opportunity and capacity similarly. Ethan's self-report indicated that he is experiencing lower opportunity and higher capacity than what the proxy respondents reported. He, his teacher, and his mother reported that he has a higher opportunity for SD at home than at school.

Ethan's self-identified goal was to make new friends by taking care to listen to the friend's interests. He felt that his goal was being achieved. His guardian reported that Ethan's goal was to keep his hands and feet to himself. He was working toward this by playing less physical games, taking medication to help regulate impulsivity, and playing in smaller groups. She reported that Ethan was having difficulty achieving this goal due to extreme impulsivity. Ethan's teacher identified "on-task behavior" as Ethan's goal. Several specific strategies were provided. The teacher was unclear as to if Ethan was achieving his goal, stating Ethan "works very hard every day to maintain focus and attention. He loves to please others. He requires many prompts, but most importantly, praise when he is managing his focus and attention."

Ethan's QoL was variable. He and his mother reported similar levels of overall QoL, though Ethan and his mother's ratings on the individual domains tended to differ. Specifically, Ethan perceived his physical and emotional QoL to be much higher than what his mother reported. He also reported a higher self-esteem though to a lesser degree. Conversely, Ethan's view of his family, social, and school life was lower than his mother's view. In particular, 25-point gaps were seen on the physical and social life domains.

Overall, Ethan appeared to prioritize social relationships. This is highlighted in his teacher's note on the SD questionnaire that Ethan "loves to please others." Additionally, Ethan's social adaptive behavior as measured by the ABAS-2 at school was significantly higher than the rest of this profile. Moreover, his chosen successful photograph (depicting a tense social interaction) was positive in the sense that his response to rejection was appropriate and psychologically productive/protective. Ethan appeared proud of being able to move away from children who indicated that they may not interested in playing with him at that time, thereby avoiding conflict. At the most optimistic, this behavior potentially paves the way for an eventual acquaintance-level friendship versus reinforcing an antagonistic relationship. However, the mere fact that Ethan was taught a response to being excluded implied that rejection was a frequent event, and that the rejection troubled him enough that he was responding poorly. It also suggests that Ethan required direct and structured teaching of positive responses.

There are a multitude of possible reasons Ethan might have been responding poorly to certain social situations. For example, he is reported to have difficulty with self-regulation/impulsivity as evidenced by the goals his proxy reporters identified (i.e., keeping hands and feet to self, and increasing on-task behavior) and his relative weakness in self-direction on the ABAS-2 in both environments. In Ethan's goals and choice of successful photos, as well as in his teacher and parent's description of his goals, we can infer that his difficulties with impulse control are pervasive. Specific strategies to help Ethan with social skills, attention, and self-regulation were reported to have been implemented at home and school. However, Ethan self-reports low QoL regarding school and, especially, social life. Ethan also reported that his self-esteem and emotional QoL were strong, suggesting that the difficulties he is experiencing in school and socialization may not yet be influencing his overall sense of self.

It is also significant that Ethan chose mathematics and not behavioral control as his most challenging activity at school, as the proxy respondents appeared to have behavioral control as high priority given the goals they identified for him. Potential reasons why are explored later in this section in the description of themes.

Alex. Alex (age 11) was a people-oriented child who asked the researcher and the special education teacher questions about their days and took great interest in their responses. He was straightforward with answers when he was confident of his reply; other times, he appeared to give answers that he thought would please the researcher. Alex's photographs can be viewed as Figure 11F and Figure 12F in Appendix F.

Alex was the only participant who chose to photograph a person. He took a photo of his special education teacher (i.e., the back of her head as per research ethics board guidelines). The comfort and ease between Alex and his teacher was clear, and it was not surprising that he took her photo for his successful photo. However, Alex, being so people-oriented, may have also felt some social pressure or may have misinterpreted the situation to mean that he would gain the favor of the teacher if he took her photo. In his SHOWeD response, he shared that the teacher was his friend and that she helps him.

Like his brother, Alex took a picture of mathematics for his challenging photo. It is also a division lesson, this time regarding dividing decimals. This is the only mathematics textbook photographed of the group. It showed that he was working on concepts approximately three years behind his grade seven level. He shared that to him "dividing is hard" and that he "had to skip it last year." He did not know why this problem existed, just that he was "not good at it" and that he should "keep practicing, I guess" to improve upon the problem.

Alex's adaptive behavior was reported to be within the extremely low range at home and within the borderline range at school. His reported strengths at home were communication and functional academics. Additionally, at school he had strengths in leisure, community use, and self-care skills. Self-direction and home/school living were consistent weaknesses in both settings. He was also weak in the social and health/safety domains at school.

Alex perceived his overall SD and capacity for SD as higher than what his guardian and his teacher reported. His teacher and guardian reported generally comparable scores. All three respondents reported similar availability for opportunities for SD.

Alex identified three goals to the researcher; save money, listen more in class, and to get more friends. He shared one specific strategy for each goal, each of which were relevant in only one context. Alex felt he was doing well in saving money, but not as well in listening in class or making more friends. His mother identified that Alex was working on organization strategies by ensuring he brings his work home from school, leaving a set of textbooks at home, and having increased communication between the teacher and herself through email and his agenda. She reported that Alex has difficulty reaching his goals. Alex's teacher reported that Alex's goal was to "maintain control over his words and actions when in a variety of social situations." She explained that Alex can misinterpret people's intentions, especially when he is in situations that involve competition. She went on to list specific strategies and identified that "Alex has made great gains" with respect to goal achievement.

Alex's ratings of his overall QoL, as well as all the domains except physical health, were higher than his guardian's ratings. His self-reported ratings were each above the child participants' group's mean. The biggest discrepancies between he and his mother were in the social and school life domains where Alex rated himself 31 points higher than his guardian in each area. His mother's scores were lower on these two domains than the average of the other guardians in the group.

In summary, Alex, like his brother, was a socially-oriented child. For instance, one of his self-reported goals was to make more friends, and he photographed his teacher for his successful photograph to symbolize the success he feels within that relationship. He reported his social, school and emotional life were each strong on the QoL measure and felt his SD to be high. His mother and teacher generally did not agree with his self-appraisals; he was rated to be low in the social domain at school and weak in areas relating to self-regulation and academics in both settings.

Again, like his brother, Alex's goals are not fully consistent with what the adult proxy respondents report his goals are at home and school. However, one of his goals was to "listen more in class", a behavioral regulation goal that separates him from the rest of the child participants. Perhaps being a year older and just outside of elementary school, his awareness of his difficulties in this area are greater and he wishes to improve. Alternatively, it is possible that Alex has become accustomed to being told to listen more in class; wishing to please others, he states this as his goal.

Participants 7(Jack) and 8(Eva) are not biologically related but are being raised in the same household by adoptive parents. Jack (age 14) was a boisterous and talkative young man. He had a strong relationship with his special education teacher and indicated to the researcher that he was usually happy to spend time in the resource room. A peer of Jack's was present in the resource room at the time of study participation; Jack was overjoyed to unexpectedly see his friend. He required some redirection from the special education teacher as the friend was working on an assignment that was due that day and Jack was distracting him. Later, Jack was notably patient in waiting for his mother to address some of her own affairs in the school office after he had completed his questionnaires and had taken his photos. Figure 13F and Figure 14F in Appendix F show Jack's photographs.

Jack. Jack chose one of his art projects to portray what he felt he was most successful at in school. His painting is of a Christian cross on a hill, slightly above and to the left of center of the viewer's perspective. Jack skillfully painted a very bright light directly behind the cross, with beams of yellow and orange shooting out from behind the intersection of the two vanes of the cross in what appeared to be an evening sky. The scene suggests great reverence for the Christian faith. In discussing his photograph subject, he shared that he finds it "fun to paint" and that it makes him calm. He went on to reveal that "all my teachers say I'm really good at painting and so does my mom." Jack said he was going to continue painting over the summer to build on his painting skills.

Interestingly, Jack chose to photograph his religion class syllabus for his challenging photograph. The top of the page showed his school name so he was instructed to cover it; he chose to cover it with his geography textbook, though he stated to the examiner that his geography course was not what he felt was the most challenging for him at school. The course title is "Old Testament Studies", and the textbook is the Bible. Jack stated in his SHOWeD responses "I know it's important but I don't get it, I don't remember all the people and saints and what they did." He went on to say, "I think sometimes it's harder for me to learn things" and that he should study harder to help him address this challenge at school.

Jack's mother and teacher reported his adaptive behavior to be within the extremely low range at home and school. Both respondents agreed that he has a strength in social skills. His mother also reported a strength in communication skills. Regarding his functioning at home, no significant weaknesses were found in his profile. At school, his teacher reported weaknesses in communication, functional academics, self-direction, school living, and health and safety.

On the AIR questionnaire, Jack's self-report of his overall SD was higher than his mother's. His opportunity for SD was reported at similar rates by Jack and his guardian. Jack's teacher declined to respond to items regarding opportunity for SD at home, thus teacher results are limited to the capacity scale. On the capacity scale, Jack's self-report was the highest; his teacher's score was the lowest by a 37-point discrepancy from Jack's self-report and 7-points from his mother's report.

Jack and his mother both reported Jack was working toward saving enough money to buy a new laptop. He would be helping his extended family members with chores and babysitting duties to earn money. Jack had yet to begin help his extended family at the time of the study, though his mother shared they would be, "work[ing] together on this so he reaches his goal." Jack's teacher identified that "passing all of his courses in grade 9" was Jack's goal. She reported that Jack does "the minimum amount of work needed" and that he "needs to be encouraged to do more than the bare minimum." She felt that Jack was going to achieve the goal of passing all his courses.

Jack and his mother were quite consistent in their reporting of Jack's QoL. The largest discrepancy was in his emotional well-being where his mother reported lower QoL than Jack did.

Overall, Jack's relative strengths in socialization and artistic endeavors and weakness in academics were apparent throughout the data. To elaborate, Jack chose a painting to showcase his most successful achievements at school, and reported that remembering the names and activities of important figures in Christianity was his most challenging. He and his mother identified the same goal of earning money to buy a laptop through helping extended family members (including through babysitting)--socially-oriented activities. Jack also was reported to have significant relative strengths in the social domain in both home and school settings on the ABAS-2. With respect to difficulties in academics, Jack's teacher reported that Jack's goal was to pass all his grade nine courses. He had significant weaknesses at school in many areas including functional academics and self-direction.

He shared some insight into his difficulties in his SHOWeD responses; this insight is potentially indicative of strong capacity for SD. For example, he stated that learning is harder for him and that painting makes him calm. Awareness of and reflection on strengths and weaknesses is important in making self-determined decisions. Further, adults likely react more positively to a child who is aware of and working on difficulties, which may lead to an increase in support. This insight may also help to explain some of his higher social scores. He also appeared to have a strong friendship with the child he happened by in the resource room, indicating that he may have appropriate social skills with his peers as well.

However, Jack's teacher indicated that Jack did the "minimum amount of work needed" at school. His strengths socially were observed in rather controlled settings, even when they occurred spontaneously. It would be interesting to investigate how he does socially with peers who do not access the resource room.

Eva. Eva (age 12), shy and friendly, appeared prideful that her teacher had trusted her with the key to the school's music room. She diligently ensured that the music room's lights were off and all items were in their proper places prior to leaving the room. She navigated the school expertly and seemed to operate with purpose. Eva had a composed and no-nonsense attitude. Her photographs can be viewed as Figure 15F and Figure 16F in Appendix F.

Eva's successful photograph was of her clarinet in its case. It is slightly off-center wherein the edge of the instrument is outside of the frame; she shyly declined when asked if she wished to take another photo to have the full clarinet in the frame. We see that she also stored a bright yellow iPod and two sets of headphones in the case. Several pink cleaning cloths are also seen in the case. Having personal effects stored in her case suggested a deeper connection with the instrument and/or band. She shared that she felt that she "worked hard and now I'm good at it." Eva further stated that she would "keep practicing, but it's not like working because I like it."

Eva chose to photograph a corrected French spelling test written on a single page of loose-leaf paper for her challenging photo. She spelled out the names of French numbers from one to 20 as well as every number on the 10's and one's thereafter (e.g., 20 and 21, 30 and 31 etcetera) until 100; she made six errors out of 35. The paper was crumpled in the lower right corner. She thought that the photograph showed "how bad" she was at French. She stated, "French is my worst class, I study for it but sometimes not." She attributed her challenges in French to a lack of practice, and reported that she wished to practice more to help herself overcome the difficulty.

ABAS-2 data from her mother and her teacher revealed Eva to be functioning differently at home than at school. Her adaptive behavior at home falls within the extremely low range, while at school her functioning was rated to be within the above average range--the highest of the group. At home, her strength was in the leisure domain. No significant weaknesses were noted within the home setting. At school, no significant strengths were reported though her self-direction was indicated as a significant weakness.

Eva's overall self-reported SD was high; her mother and teacher's ratings were similar and lower than Eva's self-report. Eva rated her opportunity for SD as the highest in the group of child participants; her mother and teacher's reports were lower. Similarly, Eva rated her capacity as higher than what her proxy reporters indicated.

Eva's self-reported goal was to read more books, and to read them more often. To do so, she had set a pace of finishing a book in two weeks, and reported that she had been doing well at maintaining that pace. Her mother identified that Eva's goal was to grow a garden at home. Eva had planted the seeds and had "put in little sticks to mark the spots." Eva was reportedly not doing so well in achieving her gardening goal as "she forgets to weed and water, and [mother does not] like gardening so [mother] forgets to remind her." Finally, Eva's teacher identified that Eva's goal was "independently checking for homework/assignments using the classroom homework board." He shared several specific strategies put in place by the adults in Eva's life to help her achieve this goal. Regarding how well she is achieving the goal, he stated that she had shown "consistent improvement throughout the year but she still benefits from teacher/Grandparent checks."

Eva's QoL self- and proxy reports were generally inconsistent. Eva rated herself higher on the emotional, self-esteem, social, and school domains. She reported a score of 100 on the social life domain, the highest of the group. The discrepancies between Eva's and her mother's report on the emotional and school domains were large at 31 points each.

Like her brother, Eva's skills appeared strongest in social and artistic endeavors as shown by her photographs and the questionnaire data from proxy respondents. Her narratives suggested that she had a positive attitude. Eva was unique from the group in that she presented to her teacher as quite capable at school. Eva also reports that she feels capable; her self-reported QoL and SD scores tend toward the highest of the group. However, the discrepancy between Eva's teacher's and her mother's assessments of her adaptive behavior is the largest of the group. This suggests that Eva may have adapted to present well at school, but at home she shows more of her struggles. Further, Eva appeared to be shy and reserved. She may not demand a lot of attention at school. Additionally, Eva's self-reported goal was school-oriented. She may be easier to manage at school than other students who do not have academic goals. Regardless of the cause, Eva generally reported that she felt she is achieving well at school apart from her French spelling which she chose to highlight as her most challenging aspect of school life.

Analysis of Photographs, Narratives, and Questionnaires

Photographs and narratives. The themes from the successful and the challenging photographs support what is seen in the children's profiles. The successful photographs consisted of 1) artistic endeavors such as music, drawing, and painting (37.5%), 2) perceived positive use of social skills (25%), 3) sports (25%), and 4) hands-on academics, specifically, a science experiment (12.5%). Significantly, no traditionally core academic subjects (i.e., reading, writing, mathematics) were identified. Further, the most academic photo of the group was of a highly engaging, structured, hands-on science experiment that would only occur a few times a school year--enjoying the experiment does not represent feeling adept at the subject. Overall, academia did not appear to be an area at which these children feel successful. Rather, these children felt they shone at what would typically be considered extra-curricular activities.

The children's narratives regarding their successful photographs were filled with positive statements. For example, the children exclaimed that they were "good" at the activities they photographed, that they wanted to have "more" of the activities, and that the activities were "cool" or "fun". Some children had insightful comments regarding why they liked or were skilled at their chosen craft. Eva said, “I worked hard and now I’m good at it” regarding her clarinet playing. Jack stated that “painting makes me calm” and that he should “keep painting”, potentially implying that practice is what allowed him to produce such skilled work. At times, however, the children’s insight was limited. Alex and Ethan, the children who chose socially-based successful photos, while enthusiastic about their successes, appeared to misinterpret some aspects of the situations they had documented. Alex spoke about the special education teacher as his “friend”. Ethan noted that when others do not wish to play with him, “it’s not fair”. Both felt their situations were generally positive and that they wanted to continue pursuing social connections/relationships despite any difficulties they may be having. Overall, all the children wished to approach and participate more in the activities they had photographed, rather than avoid them as seen in the narratives regarding the challenging activities.

Each of the challenging photos were related to academics. They overwhelmingly depicted core subjects such as mathematics and writing (75%). The remaining subjects were geography and religion (12.5% each). Each of these subjects are abstract in nature. Geography class can encompass topics that span across different timeframes, cultures, and political positions. Consideration of another person’s circumstances may also be required; theory of mind, thus, would be involved in the learning and understanding of world geography. Theory of mind is an area that is commonly reduced in people with a FASD (Lindinger et al., 2016). Similarly, learning about a religion’s main philosophies demands critical, abstract thought. However, Jack, the participant who chose religion class as a challenge at school, also identified that recall of saints’ names and why they were beatified was difficult for him. It is possible the rote task of memorization may have been disengaging him from the topic.

Overall, the children spoke of the subjects of the challenging photos with disdain. Words and statements communicating their discouragement such as “hate”, “boring”, “I just don’t get it”, “maybe I can’t”, “math is too hard for me”, and, “no more math” speckle their discourses. However, the children also speak about their challenges with perseverance. For example, with respect to long division, Ethan shared that he could “do my homework and ask for help if I’m stuck on a question” to help him learn it. Mack thought he could “keep studying” and Alex could “keep practicing” mathematics to improve skills. Summer also felt she could ask for help with her writing, and Jack and Eva both thought that further study or practice would help them address their challenges. Jack also shared that he believes it is harder for him to learn than others, suggesting some insight into why he might be struggling with certain academic skills.

Questionnaires. While the children’s photographs and SHOWeD responses provided an intimate view of their perspectives, questionnaire data regarding their SD, adaptive behavior, and QoL were acquired to integrate these findings within the larger scope of the PPCT framework. Further and more detailed information regarding the children’s micro- and mesosystems was obtained through the larger dataset supplied through questionnaire data which included guardian and teacher perspectives on various aspects of the children’s functioning and their environments. Several findings were discovered in analyzing the questionnaire data. Each questionnaire’s most relevant results will be outlined. First, the major findings from the sub-domains of the ABAS-2 are presented below.

ABAS-2. See Appendix E for a description of what each sub-domain of adaptive behavior was measured. Please refer to Tables 1D, 2D for 3D in Appendix D for further detail. Results are presented with representative percentage of overall participant group in parentheses.

Communication. Communication skills were variably reported across respondents. Generally, guardians tended to rate participants higher on communication than their teachers (i.e., low average mean on guardian measure versus extremely low mean from teachers). One guardian scored her children (Adam, Mack, and Chris; 37.5%) highest of the group, all within the average range. The remaining participants scored within the low average (25%), borderline (25%), and extremely low (12.5%) ranges in this area, according to guardians. Conversely, only one participant (Eva; 14%) scored within the average range according to a teacher; the remaining children's teacher rating scores fell within borderline (29%) and extremely low (57%) ranges. Thus, there appeared to be a considerable amount of environmental impact between home and school settings in how well children are perceived to communicate. Additionally, subjectivity regarding the respondent's perception of the child was also impactful.

Self-Direction. An overwhelming 100% of guardians and 87% of teachers indicated that the child participants' skills related to self-direction were significantly weak, falling within the extremely low range. In no case was this area identified as a strength in the child participants' overall profile. Self-direction was clearly an area of need within this sample.

Leisure. This area tended to be a stronger area for most participants according to guardians (62.5% in the average range, 12.5% each in low average, below average, and extremely low ranges) and teachers (43% each in average and low average ranges, 14% in extremely low range). Most of the items in this area were related to playing games or doing other enjoyable activities, so it follows that this area was generally strong. Difficulties in this area could indicate struggles to participate in group activities independently, challenges in being able to entertain oneself without guidance, or reciprocal play skills (e.g., appropriate turn-taking, initiating games, following others' lead in play).

Social. The social realm scores were variable based on the participant and the respondent. Two child participants (25%) were rated to have average-level social adaptive skills by their guardians; for both these participants, this area represented a strength in their overall profile. Three different children (43%) were rated within the average range by their teachers in this area, two of whose scores also represented strengths in the overall profiles. The remaining scores ranged from low average to extremely low. Item analysis was also conducted regarding the children's friendship seeking behavior, ability to keep friends, and ability to show good judgment in selecting friends. The children as a group readily sought and kept friendship, though were rated lower in showing good judgment in choosing friends.

Community Use. Overall, skills within this domain were a stronger area of functioning as measured by guardians and teachers (low average and average means, respectively). However, like the communication domain, Adam, Mack, and Chris' guardian's ratings of her children are higher (average) than those of the remaining guardians', representing 37.5% of the sample. Of the remaining participants, 12.5% scored within the low average range, 12.5% within the borderline range, and 37.5% within the extremely low range. Teachers mostly found the children to be within the average range (71%). One child fell within the borderline range (14%) and another within the extremely low range (14%). It is possible that because the items within this category are mostly related to activities that take place outside of school, teachers made generous estimates of the children's ability to independently navigate and use community buildings/resources. Further, the children were perhaps more adept at school due to routine and repeated exposure and familiarity, so the teachers may have extrapolated that the children's ease at school translated to ease in the community.

Health and Safety. Across respondents, the children were perceived to be quite low in this area. More specifically, as a group, their mean was low average when rated by guardians and extremely low according to teachers' ratings. Children with FASD typically present with high impulsivity (Khoury & Milligan, 2016). It is likely that children with impulsivity would be rated lower in this area--the items relate to following rules and showing caution in potentially dangerous situations. Further, in school settings, teachers are responsible for several children's safety; children who engage in unsafe situations are likely to stand out in their minds.

Self-Care. All guardians and 29% of teachers rated the children as having extremely low self-care skills. One teacher's ratings of self-care were within the borderline range and the remaining 57% of teachers felt as though the child participants had average self-care. Again here, as with community use, most of the items refer to activities that occur in the home and thus teachers are less likely to know where the children are at regarding these skills and may be estimating the children's abilities. Alternatively, the teachers could have been relating what they do see at school (where children may be more likely to display better self-care skills due to social desirability) and applying it to what they would assume the children could do in the home.

School/Home Living. The overall group was perceived to have averages within the extremely low range according to both parents and teachers. The score breakdowns for guardian and teacher ratings are very similar; one child scored within the average range, one within either the low average or borderline range, with the remaining children falling within the extremely low range. The domain's items relate to daily tidying, maintenance, and upkeep of the home or classroom as developmentally appropriate. For children who have difficulties with organization, initiation, and planning, it is not surprising that this area was deemed a challenge for them.

Functional Academics. According to both guardians and teachers, most of the child participants scored lower than same-age peers in this area. Specifically, 86% of teachers and 25% of guardians rated the children within the extremely low range, 62.5% of guardians rated the children in the low average range, and 14% of teachers and 12.5% of guardians rated the children as average.

Overall, the child participants' ABAS-2 scores were generally lower than same-age peers. This translates to poorer adaptive behavior at home and school, and the need for support to complete the activities of daily living. Areas requiring intact executive functioning were especially weak (i.e., self-direction, functional academics, school/home living, health and safety, self-care).

KINDL-R. The KINDL-R's items are represented by six categories related to an individual's QoL: physical well-being, emotional well-being, self-esteem, family life, social contacts, and school life. A total score is derived from the sum of the six subdomains. Scores are reported as a number value out of a possible 100. Please refer to Tables 7D, 8D, and 9D in Appendix D for an overview of how the child participants and their guardians rated them overall and on the six categories, respectively.

According to the mean scores of the guardians' ratings of the children, physical (65) and emotional (64) well-being were rated the highest, while social contacts (54) and school life (54) were tied for lowest rated. Child participants rated themselves highest on emotional well-being (74) and social contacts (69), and lowest on self-esteem (58) and school life (57). The children rated themselves slightly higher (64) overall than their guardians did (57). Thus, the children and their guardians agreed that the children's emotional well-being was generally satisfactory, and that school was an area of marked difficulty. As a group, the children did not feel they were suffering socially, though their guardians tended to disagree.

AIR. The results from the AIR can be seen in Tables 3D and 4D in Appendix D. The children rated themselves higher in total SD than their guardians or teachers did. The difference was not due to opportunity ratings; the average opportunity rating was quite similar across respondents. However, the standard deviations show there was considerable variability within the self-report group, some variability within the teacher group, and minimal variability within the guardian group. The students, thus, were divided about whether they felt they had the occasion to practice SD. These students also, as a group, felt they had substantially more opportunity to practice SD at home than at school. Their parents tended to agree, but to a slightly lesser degree. Teachers felt that the students had more opportunity at school. The children rated their capacity for SD noticeably higher than their teacher and guardians did. The teacher and guardian capacity ratings were roughly concordant.

Goals. On the AIR questionnaire, the participants were asked to identify the children's goals, what the child was doing to reach the goal(s), and how well movement toward goal achievement was going. The goals identified by most respondents were vague. For example, frequent references to behavior management/regulation were made by teachers, though specific and measurable behaviors are not necessarily defined. Alex's teacher mentioned "maintaining control over his words and actions…in social situations", and Ethan's, "on-task behavior". Chris' teacher shared that Chris was working on "managing his own behavior" and "not saying inappropriate comments".

Another common type of goal identified by teachers and guardians was organization; this type of goal was defined in more specific terms than those regarding behavioral regulation, but most also lacked clarity and detail. Further, some showed confusion around for whom the goal was for. We see Alex's guardian writing that Alex is "trying to work on organization strategies", then described several strategies that are were managed by herself and/or Alex's teacher. Eva's teacher discussed that Eva's goal was to independently check for homework/assignments; the teacher and Eva's grandfather were also checking her agenda to ensure she had recorded all the necessary information. The teacher reported that while she had shown "consistent improvement throughout the year", she benefitted from these supervisory checks. Adam's teacher reported that Adam was working on "organizing his desk". The teacher provided strategies that Adam himself was responsible for after having been implemented by the teacher (e.g., color and binder system).

The academic goals identified by the adults in the study ranged from ambiguous to highly specific. A more nebulous goal included Jack's goal as reported by his teacher of "passing all of his courses in grade 9". Summer's mother provided a moderately specific goal of "keep receiving A/A+'s in math". Mack's teacher offered the most detailed goal in stating, "In math, Mack is working to find a pattern rule when given a table of values".

The two goals that were consistent between guardian and child were rather specific. These goals were realistic and attainable within a reasonable timeframe. It appeared the children had created the goals in collaboration with their guardians and they seemed to find the goals personally meaningful.

The children's self-reported goals included academic goals (e.g., reading, continued achievement in math class), attaining money/gaining employment, and making new friends. When asked how they were going about goal achievement, many provided specific and concrete strategies they were implementing. For example, Alex reported he was "trying not to use fidget toys and not keep my head down" in relation to listening more in class. Jack said he was going to be "helping out my grandparents by babysitting my cousins and helping out with yardwork" to gain money to save up for his own laptop.

Proxy-report goals were mostly related to how the children were behaving and by extension, how the adults were functioning in their role. For instance, many of the teachers' identified goals tracked onto what is required commentary on Ontario report cards (e.g., organization, behavioral regulation). Few goals were fully concentrated on what the child's goals were. Those that were involved either the child's career choice or an activity to make money.

Themes

These data converged and diverged into over-arching themes. Namely, context appeared to influence the respondents' perceptions of the child participant. Despite this lack of consensus, there were several areas where the data came together. The children were largely socially-oriented, though had some difficulty having meaningful friendships. Academics were universally considered a challenge for the children by all respondents, and in a related vein, the children's difficulties in executive functioning skills stood out from the data. Potentially as a result, the children were assumed by their teachers and guardians to require a considerable amount of support. This led to a potential over-estimation of the pathological nature of the children's behavior. The themes are described below.

Evaluation of the child participants was context-dependent. In general, teacher and guardian respondents gauged the same child participant differently on measures of adaptive behavior and SD. For example, five guardians perceived the children's communication skills to be considerably higher than their children's teachers did. Eva's teacher overall felt that Eva was functioning well, even above what would be expected for her age, while her guardian rated her functioning as quite low overall. Additionally, four teachers rated the children's ability to self-care much higher than their parents did, and six of seven teachers rated the children's capacity to engage in SD lower than the guardians. Opportunity for SD skill practice was perceived to be different across settings. The guardians and children tended to believe there was more opportunity at home, while the teachers leaned toward believing the children had the most opportunity at school.

Similarly, the child participants' responses on their self-report questionnaires regarding QoL and SD varied from those of their guardians and teachers. In general, students had higher perception of their capabilities. Their self-reported capacity for SD on the AIR was substantially higher than what their guardians and teachers reported it to be. Their overall QoL was also consistently higher than what their guardians rated them. With respect to goal achievement, 62.5% of students reported they were achieving their goals, compared to 0% of guardians and 25% of teachers. It is little wonder that the children were more positive concerning their capacity since they were so much more likely to feel as though they were achieving their goals. The goals that each group reported varied widely and many adults were likely rating the children on goals that the children did not write themselves. For example, teachers often identified behavior-related goals for the children, while the children identified different types of goals. One rather common goal the children set for themselves was to attain money. Money is significant here; when an individual has money, they are more independent. They have control over that money in that they choose what to do with it. The children often reported they would like to use their money toward leisure time activities, the area in which most children were identified as having strength. It follows that the children would wish to use their energy toward gaining some level of financial freedom if the adults in their lives were placing (most often necessary and helpful but perhaps at times overly) restrictive limits on them.

This general lack of consensus points to several issues that will be discussed in the next section. Despite some considerable disagreement between respondents, there were meaningful areas of concordance discussed next.

Socially oriented students with variable successes. The children had difficulty bridging the gap between having the skills necessary for successful socialization and applying the skills. Some children appeared to have poor insight; for example, both Ethan and Alex described social situations for their successful photographs which they did not fully understand. In her QoL questionnaire, Summer reported that she only sometimes plays with friends despite always getting along with others. Further, given the discrepancies between many of the children's social QoL and their reported social abilities on the proxy ABAS-2 and QoL questionnaires, it is possible the children are misperceiving social situations to their favor. Item analysis from the social domain of the ABAS-2 showed that overall, most of the children were seen to have poor judgement in choosing friends. Weak judgement is surely to impact the development and continuation of meaningful friendships.

Academics identified as a challenge. All the children chose to photograph academics as their most challenging aspect of school, almost all of which were core subjects such as mathematics and writing. In addition, the children were rated quite low overall on the functional academics subdomain on the ABAS-2 by both guardians and teachers. The children's QoL related to school life was consistently low on self and proxy reports. Poor executive functioning can derail a child's efforts in academics. These children appeared to have significant difficulties in executive functioning.

Reduced executive functioning skills. Children with FASD are now known to have difficulties in executive functioning (EF) skills (Khoury & Milligan, 2016), and the current study's children participants are no exception. As mentioned, the self-direction subdomain on the ABAS-2 was consistently the lowest in the overall sample. Many of the items within this domain are directly related to EF skills. For example, the measure assessed characteristics such as planning, organization, emotion regulation, initiation, focus, and time management. In addition, teachers and guardians made several comments regarding the children's need for reminders, prompts, and support to achieve goals. Thus, the amount of support the adults reported the children needed is consistent with the concept that goal-setting itself can require a considerable amount of EF skill.

Support assumed. The support identified in the data often indicated helpful and necessary accommodations and modifications to the school and home environments or expectations. The adults identified that the children received adult-guided support in the form of reminders/follow-up, prompts/check-ins, frequent breaks, guided reflection on situations that did not go right, having selected adults to go to if the child feels like they need support, and the provision of praise and encouragement. However, at times, the strategies the adults shared were restrictive.

Restriction of choice is problematic. Too much restriction reduces SD and, consequently, QoL (Wehmeyer & Schalock, 2001). In the current study, Ethan and Alex's teacher and guardian provided some of the more restrictive strategies of the group (e.g., take medication, play less active games). While Ethan and Alex each identified they would seek support in the face of challenges at school, they both had decreased self-reported SD scores as compared to the rest of the group. They also each reported lower opportunity and higher capacity for SD than their teacher and parent did. In their cases, they may be over-reliant on adults.

Risk of over-estimating pathology. Several of the behaviors that adults in the study identified as problematic are not always necessarily abnormal or outside the realm of what would be expected for a child at the chronological and/or developmental age level of the child participants. The children in the current study were reported to avoid work and organization tasks. There were frequent remarks regarding reminding the children to stay-on or complete tasks. These issues certainly prove difficult to manage at home and in school when extreme. However, many children avoid work, especially if it is difficult. Children and youth alike need structure and guidance to develop strong organizational skills. Reminders are commonplace for children of lower developmental age, as many of the children in the current study appear to be given their ABAS-2 scores.

Moreover, some of the specific statements offered by the adults point to possible overly negative interpretations of the children's behavior. For example, Chris' teacher wrote that Chris was "not learning from mistakes". Alternatively, rather than not learning, Chris may struggle to generalize lessons from one situation to another, or he may be highly impulsive and have significant struggles in thinking through consequences. Jack's teacher stated that Jack does the "minimum amount of work needed". This may be true, or it could also be that Jack's efforts are sufficient for what he feels is enough to reach his own goals. Jack could also require more support, or the amount of work expected from him is outside the limit of what he is capable of. More information would be required to determine what is the underlying cause of these behaviors rather than interpreting them at face value as ill and treating them as such.

Perhaps in part due to the less-favorable analyses of behavior by the adults, numerous strategies toward goal completion put forth by the teachers and guardians in the study were rather restrictive. For example, guardians and teachers shared they were implementing such strategies as having the child take medication, play less active games, maintain eye-contact during lessons, and play in smaller groups. These interventions could be useful as part of an overall treatment plan for behavioral regulation, but without additional support that incorporates the child's goals, needs, and strengths, these strategies lack meaningful and lasting efficacy.

Connection to the PPCT Model

Consistent with the PPCT model of development, the current findings suggest that individual and environmental characteristics contribute to the SD of children with FASD. The processes between the children and their environments appear to play a significant role in their SD, and subsequently, their QoL. For example, the findings from the present study suggest that the child's EF appears to hinder their ability to function independently and can lead to more restrictive environments. However, the more restrictive the environment, the less an individual relies on themselves to plan, organize, and regulate their daily activities and goals (Bernier, Carlson, & Whipple, 2010; Carter et al., 2006; Felce et al., 2002; Mansell et al., 2003), suggesting a negative feedback loop wherein the child's symptoms of FASD evoke restrictive practices and environments from adults, which can lead to increased dependence, outbursts related to wishing for greater autonomy, and further pathologization of the child's behaviors. Reduced EF skills may rest the core of the child's difficulties, where lower abilities in social skills and goal setting result in weaker academic and adaptive behavior scores and more support assumed by adults. These factors lead to more restricted environments and ultimately, lower SD and QoL. See Figure 1 below for an illustration.

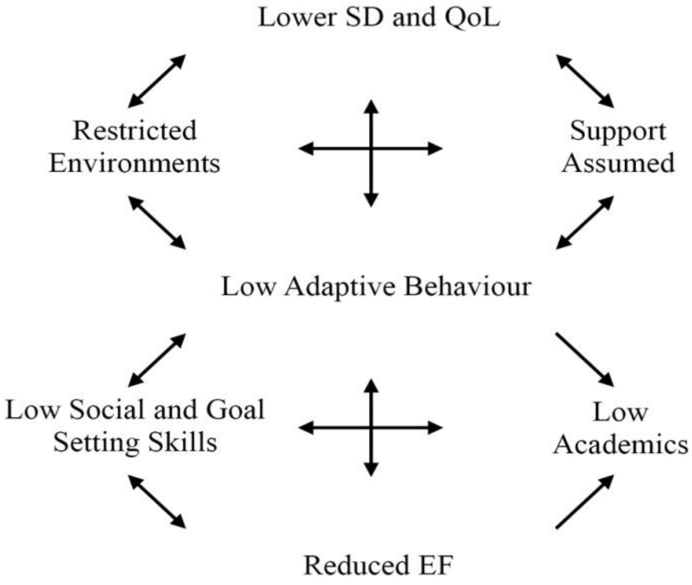

Figure 1. Cascading and recursive negative impact of reduced executive functioning skills.

It follows that the interaction between the components (i.e., the child's individual characteristics, the environment including macro-level contextual factors such as policy and stigma, and time) either enhance or reduce the child's SD skill levels. See Figure 2 below.

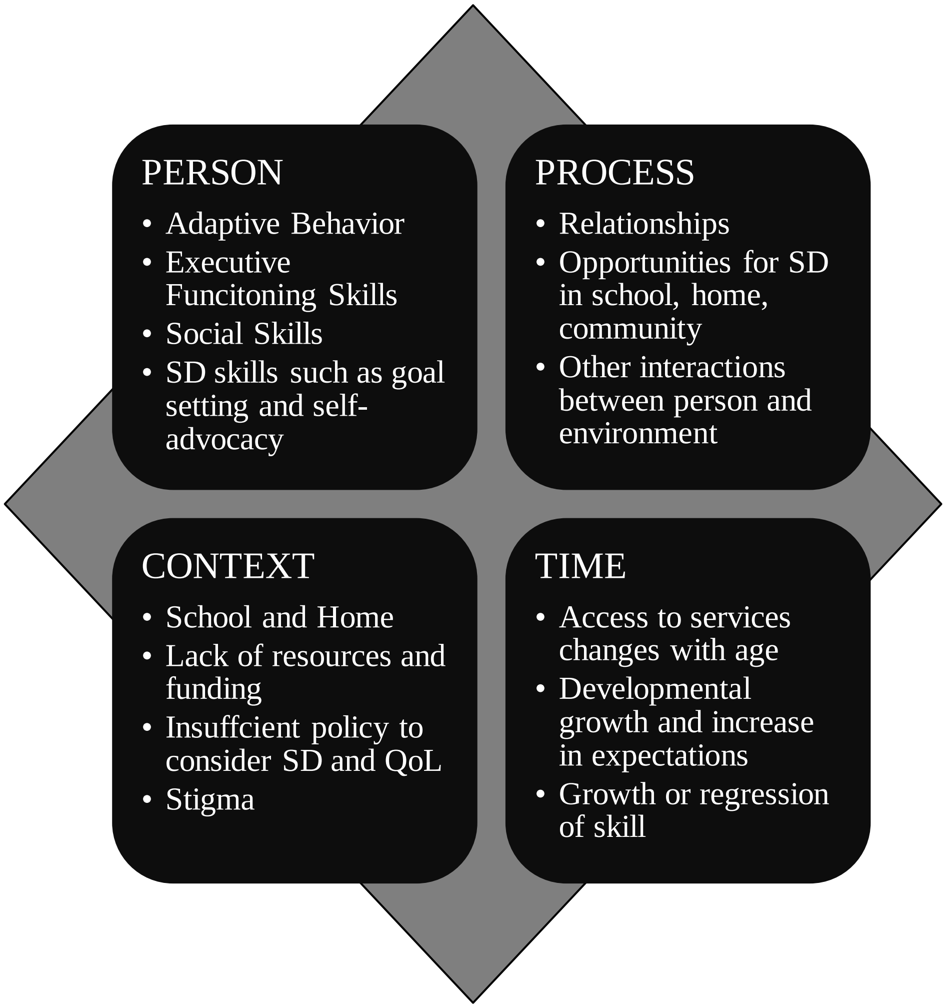

Figure 2. Factors involved in the SD of children with FASD within the PPCT model

Specifics and elaborations of these relationships are described in more detail in the discussion section.

Summary

The findings of the study show there were discordant beliefs regarding the children's SD, adaptive behavior, and QoL between teachers, guardians, and children who have been diagnosed with FASD. However, the children in this study were consistently seen to have academic and EF challenges. The adults in their lives reported that the children required a significant amount of support; there is potential for the children's behavior to be understood as pathology. Overall, each of the main themes are interconnected across multiple levels and occur in a process, such as explained by the PPCT model. Discussion of the overall findings, limitations of the study, implications of the findings and directions for future research follow in the next section.

Discussion

The current study set out to explore the SD of children with FASD, particularly at school. Adaptive functioning, QoL, and the processes between the children and the people and environments they interact with were investigated using photographs taken by the child participants, short narratives with the children regarding their photographs and questionnaire data including open-ended response options. These factors and the method used to explore their relationship with the development of SD are theoretically aligned with the PPCT model (Bronfenbrenner & Morris, 2006). The PPCT model was used to frame the study and versions of this model have been documented in research involving SD, QoL, and children's education (Schalock, 2004; Shogren et al., 2007; Wehmeyer & Schalock, 2001; Zhang, 2001). The child participants' photographs elucidated the nuances of these relationships. Children who have previously had very few opportunities in research to express their opinions and experiences at school had their voices heard. The relationship between various elements of their environment, namely their SD skills at home and school, their QoL, and their adaptive behaviors at home and school were explored. These elements were compared with the themes from the child's photographs and the discussions that arose from them, deepening our understanding of the child's SD. Never has SD been explored in children with FASD, and this is the first time a bioecological theory of development has been applied within school-based research involving children with FASD; thus, the study provided a unique and more thorough view of how children with FASD are self-determined, most principally at school.

The main themes resulting from the analysis were (a) the evaluation of child participants was context-dependent, (b) students were socially oriented but variably successful in socializing, (c) academics were identified as a challenge, (d) reduced EF skills were identified in all child participants, (e) support was assumed by adult participants, and (f) there is a risk for over-estimating the pathological nature of the children's behaviors.

Reduced EF skills appeared to be at the core of the children's difficulties. Their EF difficulties resulted in poor social skills and goal setting. Academics and adaptive behavior were also overall reduced, secondary to difficulties in EF, social skills, and goal setting. As a result, the adults responsible for the children in the home and school settings tend to assume they will require support to complete their daily activities. This support is necessary, but can also restrict the children's opportunities to make independent choices and grow. Thus, their SD and QoL is reduced.

In terms relevant to the PPCT model, we see that person-specific and context-specific factors interact to elicit change (either in a positive or negative direction) in the developing child. The child's EF, adaptive behavior, social skills, and SD skills such as goal setting and self-advocacy impact how the child interacts with their environment, and how their environments respond to their actions or presence. The relationships the child has with others in their environments effect the process of their SD development. Systemic influences also impact on their SD development, such as lack of resources and funding, insufficient policy in considering SD and QoL in school settings, and stigma. The child's opportunities for SD development are subsequently affected. Time changes how the factors may influence the child's SD development; for instance, access to services, developmental growth and subsequent increase in expectations, and potential regression of the individual's skill development each impact how the child will develop SD.

These findings shed light on how to better serve this population, which has received little attention at the various levels of education policy in Ontario (Duquette & Orders, 2010). Results also inform on what elements of school certain children with FASD relate to success and failure, enabling more focused teaching strategies to develop. Children and families impacted by FASD have another source of information to draw from when attempting to self-advocate for better educational environments and in battling the psychosocial effects of stigma. Further, the results inform school psychologists and other clinicians working with children with FASD on eliciting meaningful engagement and information-gathering through means other than verbal interviewing. Systemic and contextual factors are highlighted for clinicians and stakeholders to consider when interpreting information required when developing interventions for children with FASD.

The following discussion expands on the themes described above. The posited connections between the themes and the relationships between individual elements within the PPCT model are broadened. Further detail regarding the limitations of the study, implications of the findings, and directions for future research conclude the dissertation.

Evaluation of Child Participants was Context-Dependent

In the current study, teachers and guardians tended to rate the same child differently regarding the child's adaptive behavior and SD. For example, guardians generally rated the children higher than teachers did on the communication scale of the ABAS-2, suggesting that guardians understand their children more easily than teachers do, or that the children are communicating more clearly at home than at school. In either case, this finding suggests that teachers would benefit from collaborating with the families of children with FASD to help them understand how the child communicates.

Teachers tended to rate children higher than guardians on the self-care scale of the ABAS-2. This makes some intuitive sense as teachers are less likely to see or notice how the children independently take care of their personal hygiene given that they only see them in the school setting after their guardians have helped them off to school. This highlights the importance of taking context into consideration in the interpretation of ostensibly objective measures.

Opportunity for SD practice was measured by both teachers and guardians to be higher in their respective settings; teachers generally rated the school environment as higher than home for opportunity for SD practice, guardians rated the home as higher. This is clear bias, and points to some level of discordant relationships between home and school. Researchers and practitioners should continue to reflect on the possibility of bias in the interpretation of data.

Overall, the students had higher perceptions of their capabilities than the adults in their lives did. Regarding QoL, these findings are like those of Rotsika et al. (2011). In their study, mothers of children with a learning disability rated their children lower on scholastic QoL and higher in physical and emotional well-being than the children rated themselves. The current study's QoL findings mirror those of children with a learning disability, suggesting that children with FASD and learning disabilities may face similar challenges.

Proxy and self-reports have historically differed with regards to QoL, with some conjecture around if children or those with intellectual disabilities lack the ability to adequately or meaningfully self-assess or compare to others (Rotsika et al., 2011). The child participants in the current study did tend to respond quite literally to questionnaire items and to the narrative's semi-structured queries. Additionally, developmentally, children are more positive and optimistic which can color their perceptions of their abilities.

Alternatively, it is possible that the children's self-report is just as accurate as those of proxy reports. Indeed, some children in the current study noted insight about their brain function being different from their peers. As a group, their self-reported QoL regarding self-esteem was lower, not higher, than that reported by their guardians. Their inner lives are not objectively seen and thus special attention should be paid to any emotional distress children might be reporting. Further, the optimism they may exhibit earlier in life could transform into negative emotion as they age and encounter more failures (i.e., possibility for learned helplessness); their development should be monitored. The children's self-assessments should be taken seriously and within the context of their limitations.

The differences in opinion between the children and their guardians and teachers can be partially attributed to differences in the respondent's focus. Summer, for example, reported feeling among the lowest of the group in relation to school QoL and emotional well-being, and obtained the lowest score in self-esteem though her mother reported her to be much higher. For a child with difficulties and differences, their experience of living in a comparative struggle is likely to be a strong focus in their minds. A parent would no doubt also be thinking about their child's struggles but may have a greater focus on areas that are more observable, such as grades at school, behaviors, or interactions in parent-teacher conferences.

The influence of gender on an individual's SD has been seen to have little impact in one study (Wehmeyer & Garner, 2003), females were shown to have higher self-reported scores of SD in others (Lee et al., 2012; Shogren et al., 2007), while an Italian-based study found males to have higher SD scores (Nota et al., 2007). The present study's two female participants did have higher SD scores, which is in-line with the more recent American-based studies of Lee et al. (2012) and Shogren et al. (2007). These girls were also viewed as higher functioning in general by their guardians and teachers than the boys in the study. A future direction for research is thus how gender may be considered when interpreting information regarding their SD.

Socially Oriented Children with Variable Successes

The children in the current study reported higher social skills and capacity for socialization than their guardians and teachers had reported observing. Some children misunderstood social situations, and most were seen to have weak judgement in choosing friends. Poor social judgement and gullibility tend to be prevalent in individuals with FASD (Greenspan, 2008).

The findings of the current study are reflected in another qualitative study involving adolescents and young adults with FASD (Duquette et al., 2006a). The participants in this study also appeared to have an inflated sense of their own social skills as compared to their guardians' reports. Therefore, a trend is seen in this population where social abilities are inaccurately self-perceived. These children are motivated for social success, so despite their lack of awareness of their difficulties, they would likely be quite open to learning skills to improve friendships and to get along better with others.

Pierson et al. (2008) found that when using teachers as a proxy reporter, social skills were related to SD skill development. There was a process between a student and teachers wherein the student's social skills, or lack thereof, significantly impact the teachers' perception of the student's capability of learning SD skills. This pessimism would de-motivate teachers from making extra efforts required to teach SD skills to the child and to create opportunities for the child to practice these skills. The importance of not only improving the social skills of the children but of also having teachers be aware of this potential bias is highlighted in these findings. For children with FASD, teachers must be especially understanding of the children's difficulties and be willing to overcome their perception of lowered capacity to foster SD in the classroom.

Academics Identified as a Challenge

It is striking that each of the students in the current study chose academics to photograph for their most challenging school characteristic, with the majority picking core subjects of mathematics and writing. They made several negative statements associated with the subjects, and rated themselves low on scholastic competence. Their teachers and guardians agreed that academics were challenging for the students.

With respect to QoL specifically, in one previous study no differences were found between typical peers and children with a learning disability on the school life domain of the KINDL-R self-report (Ginieri-Coccossis et al., 2013), a finding which would likely be inconsistent with the current study's FASD group given their low scholastic self-perception. Overall, children with FASD appear to have significant difficulty with academics and may feel more negatively about their difficulties than children with a learning disability. Support for their difficulties is imperative, including emotional support to deal with negative feelings regarding the academic struggles. Many of their academic difficulties may stem from difficulties in EF, which is discussed next.

Reduced Executive Functioning

Executive functions (EF) are the cognitive processes of higher order that direct planning, working memory, set shifting, and inhibitory control (Bernier et al., 2010; Brown, 2006). Three specific areas of EF (i.e., inhibition, working memory, and set-shifting) have been especially implicated as the most effected by FASD (Khoury, Milligan, & Girard, 2015). These processes are involved in goal-directed behaviors, a cornerstone of SD. They reflect the ability to start and finish a task in a timely fashion without assistance and without excessive exertion. Additionally, EF is not linked to intelligence (Brown, Reichel, & Quinlan, 2009).

The results of the current study suggested that the participants' level of EF impacted negatively on their academics, social skills, and their access to opportunities for practicing SD skills. Elements of EF are found embedded throughout the entire ABAS-2 measure, especially within the self-direction domain. For example, the self-direction items included if the child could control anger/feelings when disappointed, whether projects are completed on time, presence of an awareness of time, and the degree of prioritization of tasks. Other areas on the ABAS-2 evaluated how independently they can organize and engage in their own leisure time, if they were self-reliant in the navigation of the neighborhood and in both familiar and unfamiliar establishments. The fact that these participants generally scored low overall on the measure indicates that they require support for the full development of SD. This also gives reason to why children felt more successful in areas where EF is not as taxed.

This finding has important implications for how and where to target interventions. If interventions are clear, goal-oriented, and aimed toward improving inhibitory control, working memory, and set shifting, then it follows that the adults in the child's life may be more likely to offer opportunities to the child to practice autonomous and productive behavior. Indeed, there is evidence that supports this.

A study by Bernier et al. (2010) showed that encouragement and support of autonomy from parents was the strongest predictor of EF at 12-15 months, again at 18 months, and a third time at 26 months of age, regardless of cognitive ability and the level of maternal education.

Parenting style influenced development of EF, specifically in terms of impulse control, working memory, and set shifting. Parenting was measured in terms of three parameters: scaffolding, sensitivity to the child, and mind-mindedness which is labelling emotions and the mental processes that allow us to self-regulate. Further, when children were provided with autonomy support from their mothers over their early years (from birth to age 3), their EF was enhanced by the time they reached 4 years old (Bindman, Pomerantz, & Roisman, 2015). The findings are especially compelling given that mothers' cognition, warmth, and the child's cognition were covaried. This knowledge would be vital to impart to new parents of children with FASD.

In home and school settings, the responsibility to manage EF is often on the child without necessarily addressing the environmental components that impact the child's self-regulation. Special attention should be made to adapting environments for those with EF difficulties to set children with FASD up for success. With adapted environments, children would also have a greater chance of practicing their SD skills autonomously.

Support Assumed

Many of the strategies and comments made by the adults in the current study reflected beneficial modifications and accommodations to the expectations or environments of the school and home. The children were reported to require substantial adult-guided support. At times, the strategies mentioned were restrictive and may have underestimated the children's ability to make good autonomous choices.

Most of the children participants' successful photographs centered around active, hands-on activities. For example, Mack's photograph of a science experiment showed that his teacher had provided clear instructions. Other adolescents and young adults with FASD have indicated that they preferred teachers who integrated concrete and clear instructions/activities into their lessons (Duquette, Stodel, Fullarton, & Hagglund, 2006b), perhaps because these and other accommodations are not restrictive and instead foster the child’s SD. Further, the adolescent and young adult participants in this study described seeking independence in the classroom through asking for an amount and degree of work that was adapted to their level, rather than requiring constant one-on-one support to keep up with the class. These accommodations and modifications to a classroom environment would make SD skills easier to learn and practice.

Individuals with FASD reported that praise and positive reinforcement was integral for shaping of positive behaviors (Duquette et al. 2006b), consistent with one teacher in the current study reporting that praise was used as a strategy with one of the child participants. This practice is not restrictive, though does provide guidance and support to the individual who needs it, an excellent strategy for fostering SD.

Those students in the current study (Ethan and Alex) who themselves spoke about seeking support did have a lower perception of their capabilities as compared to the other participants in the study. Ethan and Alex’s teacher and parent identified goals are somewhat restrictive, as are the strategies they discuss. These findings, in combination with other elements under the umbrella of this theme, suggest that when a child’s abilities are estimated to be below what they are capable of, their environment becomes more restricted than is necessary, and it is possible their self-perception of their own capabilities decreases. This process runs the risk of over-estimating the pathological nature of the children’s behaviors, and in turn reduces opportunity for SD.

Risk of Over-Estimating Pathology

It is natural for the adults who are responsible for a child’s safety to wish to prevent negative situations from occurring, and the sense of urgency can only mount when the young person is identified as having difficulty with impulse control and as having poor judgement. The development of effective SD skills, conversely, require a growing individual to have the freedom to make mistakes and fail. Those with challenges in making non-impulsive decisions likely need even more practice than those who do not. This statement is not to imply that supports, guidance, and purposefully created opportunities for practice are not required. It is a call for more comfort in taking appropriate risks when allowing the child to choose, and to offer the correct amount of support (including predictable and consistent consequences for actions) to the child to make risk-taking safe for all involved. After an extensive review of literature, including that which conducted qualitative interviews of children and adults with and without disabilities about the factors that influenced the development of their SD skills, Field and Hoffman (2002) identified quality indicators of school environments that promote SD skill development. Two of these indicators involved having consistent and predictable consequences for actions, and the encouragement of appropriate risk-taking. Finding the balance between support and allowing for safe risk-taking will be the challenge for teachers and guardians of children with FASD.

Connection to the PPCT Model

The PPCT model can be applied in understanding the results of the current study in many ways. Please refer to Figure 2.

Process. The processes between the children and the adults in their lives serve to drive development forward or backward (Bronfenbrenner & Morris, 2006). For example, we saw two guardians (i.e., Jack and Eva's guardian, and Chris, Mack, and Adam's guardian) identify goals that appeared to reflect the children's interests. However, Jack and Eva's guardian had more productive and structured ideas of how to support the children in achieving their goals such as identifying necessary steps toward goal achievement. In this example, Jack and Eva are likely to have a better chance at learning the skills required to achieve the goal independently, and thus have greater opportunities for SD.

The children's peer interactions can serve the same purpose, as we saw in Alex's case where he considered his reaction to peer rejection to be a success. Despite having a negative social experience, Alex had learned to manage his anger and appeared hopeful about trying to play with other peers instead. The potential effect of the teacher and guardian's personal beliefs (i.e., positive, open attitude versus prejudiced) on the proximal processes that the child engages in is profound. If the adults assume that the children need support where it is not required, the children's access to opportunities to practice SD are limited, and their environment is restrictive. In these circumstances, SD is substantially diminished.

Person. The children's characteristics such as their acquired skills and knowledge impact their SD development. For example, a child's ability to independently navigate community establishments will influence their access to resources. This access can build their SD, while the lack of access will limit it. Some children may also have characteristics that encourage or attract progressively more complex interaction between the person and the environment that would push their development forward. For example, a child with positive social skills would likely attract positive interactions from other people.

In the case of EF difficulty, it has been discussed and shown in Figure 1 that this can negatively impact several areas of the children's lives including social skills, goal setting, adaptive behavior and academics. These characteristics lead to adults' assumptions that the children need support, which then potentially restricts their environments, ultimately leading to lower SD and QoL. The negative feedback loop can be ameliorated not only by targeting EF skills, but also through increasing children's opportunities to act in a self-determined manner such as offering more choices in daily tasks, or teaching self-advocacy skills. This practice could also improve children's QoL.

Context. Regarding context, the environments that the children inhabit either help or hinder efforts to support them (Bronfenbrenner & Morris, 2006). At the mesosystem level, their school and guardian's access to resources will influence if they will be able to help the children set reasonable goals, teach SD skills, or provide opportunities to practice them. At an exosystemic level, education systems may not have the framework to support children with FASD, especially regarding SD skills or areas that influence QoL. Policies that are imprecise or vague further complicate access to resources for families and teachers. No direct evidence was found in the current study's data for a lack of resources or policy influence detrimentally impacting the child participants' SD, though it is thought that a longer-term study would reveal these difficulties given the results of the relevant literature.

Similarly, while no direct evidence indicated that the child participants were experiencing stigma, it has been established that stigma can influence people's perceptions of an individual's behaviors (Abdullah & Brown, 2011; Heflinger & Hinshaw, 2010). Public stigma is related to psychological distress in many populations, including those with concealable stigmatized identities such as those with intellectual disability (Dagnan & Waring, 2004), and children with mental disorder (Martin, Pescosolido, Olafsdottir, & McLeod, 2007) even when effective treatment is known to be underway (Pescosolido, Fettes, Martin, Monahan, & McLeod, 2007). This contextual factor can thus also influence people's interactions with children with FASD, and negatively impact the children's SD.

Time. Another variable to consider is time. The nature of study made it unfeasible to directly observe or measure what was happening when a proximal process was occurring and how frequently the process occurred. However, regarding chronosystemic influences, various factors can be considered. As children age, they desire more independence. The number and complexity of expectations placed upon them also increases. Ideally, their skill level grows approximately in tandem with their need for and expectations of autonomy. In the cases where support is required, or there is regression of skill due to such factors as trauma or change in access to services, there is the risk of over-compensating and restricting the individual's SD.

Limitations

There were limitations to the current study. For one, the study was subject to self-selection bias. It is possible that parents who agreed to participate in the study are more involved in their child's education and other life-enriching activities; thus, they may offer more opportunities for SD at home. These opportunities for practice may have given the child skills to be more self-determined at school. Additionally, the guardians' involvement at school may have in turn increased the teachers' attention on the child. It follows that these children's QoL may also be artificially higher than the average child with FASD.

All guardians were adoptive parents of the children, including one biological grandmother. While having adoptive parents involved in the study is consistent with previous qualitative work in the FASD field (Duquette & Stodel, 2005; Duquette et al., 2006a), it might be beneficial to have more biological parents involved to increase the understanding of that population.

Inherent in all qualitative study, the results of the analyses are open to alternate interpretations. Alternate interpretations were discussed wherever possible; however, contact with participants did not occur post-data collection so theme verification did not take place. Further theme verification with participants may strengthen future studies of this type.

The children's responses to their own level of SD or QoL were generally quite different from their adult proxy respondents. The data were triangulated; however, further validation of the children's responses could have taken place through a method brought forward by Hughes et al. (2013). These researchers asked their participants to give examples to corroborate responses. If the example did not match the response, the answer was nullified. The drawback to this approach is that the process would require a lengthy session with the children, which in turn may result in more difficulty with recruitment. Future researchers may wish to consider and weigh this option for further verification of data from children with disabilities.

While the sample size was considered sufficient for the purposes of the current study, only two female students participated. A gender-matched or larger sample that included more female or gender non-conforming individuals would have been ideal; however, low recruitment proved to be limiting in this regard.

One of the more salient findings of the study was that the children exhibited difficulties in areas relating to EF. Unfortunately, during the development of the study no specific measures of EF were included into the study design. Given that it has now been well-established that difficulties in EF is widespread within the FASD population (see Khoury, Milligan, & Girard, 2015), future researchers in the field would be best advised to include at least one measure of EF, preferably from a neuropsychological psychometric battery as opposed to teacher and/or parent report.

The researcher attempted to take socio-cultural influences into account when situating FASD in societal and historical context, as well as in the analysis. However, more information would have been beneficial in interpreting the data and understanding the perspectives of all the participants. Socio-economic status of the families, school resource levels, and even ethnic background of the participants could be helpful. The current researcher wished to highlight the idea that FASD is not unique to certain populations, and out of respect for those populations she did not ask participants about their ethnic background. However, this information could be helpful in providing more targeted resources to those communities that may have greater prevalence rates by understanding the ethnic context when situated within a broader socio-cultural background. Should future researchers decide to include this information, it is highly encouraged to place the ethnic background in socio-cultural context when interpreting data.

Implications and Future Directions

Practice. The results of the current study revealed several areas in which interventions for children and youth with FASD should be targeted. Namely, developing EF, building social skills, and addressing secondary symptoms of the disorder are suggested. Recommendations for using a systemic approach, working with families and the role of school psychologists were also informed by the findings.

Build on EF. The current study highlighted that difficulties in EF in children with FASD may create a negative and pervasive effect on the child's overall functioning and well-being. Recent research has identified that children with FASD can make gains in EF with intervention; for example, a study has shown increased EF-relevant grey matter in children with FASD after having self-regulation therapy as compared to healthy control and delayed-treatment control groups (Soh et al., 2015). This intervention consisted of 12 weekly sessions, with each session lasting approximately 1.5 hours long. Children received cognitive behavioral and sensory integration training, the procedure of which would be helpful in guiding future practitioners in building this population's EF.

Bernier et al. (2010) found that very early (e.g., prior to 12 months of age) behavioral support from parents to encourage self-regulation made measurable impact. Specifically, scaffolding the child's activities rather than completing them for the child, mind-mindedness where the parent labels emotions and states aloud how to cope with strong feelings, and sensitivity to the child's emotional state each helped to foster the child's own EF. Additionally, Bindman et al. (2015) found that autonomy support in the first three years of life lead to greater autonomy by age four. Therefore, efforts to build the EF skills of children with FASD should begin early and continue throughout their development.

Social skill training. Children and youth with FASD in the current study were identified to have difficulties with social skills, despite having a strong desire to connect with others. Social skill training in addition to EF development would greatly benefit these children who experience such disparity between their ability and their desire to make and keep friends. There is evidence that social skill training can benefit children with FASD. According to a quasi-randomized control trial study of 100 participants investigating the effectiveness of social skill intervention for children with FASD, social skills training combined with parent training was effective in increasing knowledge of social skill (O'connor et al., 2006). Additionally, parents in the study also reported fewer problem behaviors and an increase in usage of social skills, though teachers in the study did not report any differences (O'connor et al., 2006).

Address secondary symptoms. Poor self-esteem and low academic confidence were identified as problematic for many of the child participants in the current study. Awareness and monitoring of the development of these secondary symptoms should be part of treatment and individualized education plans for children with FASD. Early intervention including teaching the children coping strategies at first signs of these issues would help assuage the impact of the secondary symptoms. Adults should also encourage activities that bolster the children's confidence, such as the creative or athletic endeavors photographed by the children in the current study. Further, mathematics was identified as a concern by the child participants, and as such, specific interventions for mathematics such as that proposed by Kully-Martens et al. (2018) would be advised.

Use systemic approach to intervention. The results of the current study suggest that interventions at school require multiple levels of support, from focus on the child themselves, to the guardians, teachers, and school system at large. Millar et al. (2017) identified several factors that should be addressed in a school that educates children with FASD including child-level factors such as personalized learning and interventions that are child-specific, adapting the expectations and environment to the child's ability level. School-based factors highlighted that children with FASD will require adapted environments, teaching, and disciplinary measures. Partnership with other agencies including medical, social, and families is encouraged.

Children with FASD would benefit tremendously from having access to classrooms and teachers that are accommodating to their individual needs. This would entail taking the children's interests and goals into account when planning individualized education plans. Some of the children in the current study had goals identified for them that appeared to be goals of the adult who wrote them as opposed to goals originating from the child. Systematic approaches to understanding what is important to the child, as well as what is required from the child to attend school successfully, is necessary to build the children's SD skills. Further, setting the children up for success would require an environmental approach where the child's sensory needs are considered. Many children in the current study indicated they felt negatively about academics;

some of these negative feelings could decrease when the children are more physically comfortable in their surroundings while they learn.

Teach families about goal-setting and long-term impact of FASD. One guardian's identified goals for her children (Mack and Adam) were related to career choices, and the strategies suggested to attain goals were not the most helpful. Families should be educated regarding the long-term trajectory of the disorder and the importance of realistic, attainable goal-setting in aiding children gain the skills to make more independent and positive choices. Resources should be provided, including opportunities for direct instruction of strategies to help children set and meet goals that are meaningful to the child and attainable with minimal support. Nebulous goals are detrimental to progress. Without specificity of goals and the ways to attain them, the child and their guardians, teachers, and other relevant stakeholders (e.g., special education teachers, educational assistants) will aim focus on divergent areas, thus confusing the child and diluting the efforts of the adults in their life. Additionally, it would difficult if not impossible to understand student's levels of SD without well-defined goals.

Additionally, the children's interests, strengths, and weaknesses should be considered when creating goals. Summer's guardian, for example, fostered Summer's interest in dance and art and integrated these into her extracurricular activities. However, the goal Summer identified related to academics, though was a perfectionistic, all-or-nothing goal of 100% in mathematics. This goal is not realistic for any child, and sets up the child for failure. Allowing space for mistakes is important for emotional and academic growth.

Role of school psychologist. The school psychologist, in addition to their role in psychological and psychoeducational assessments, intervention, and consultation, can encourage the creation of reasonable goals for the students that the stakeholders in the children's development are aware of. The quality of the goals identified in the current study was low and the goals for the students were highly inconsistent between respondents – both adult and child participants would have benefitted from guidance. A suggested goal is the integration of learning and practice of SD skills in the home and school. The specific SD skills, how to teach them, and how to create opportunities for practice would be specific to the child and their home and school environments.

The school psychologist can adapt the methodology of testing and intervention, perhaps by way of eliciting discussion through photographs, to better serve this population. The use of photography in practice can serve as a model for other stakeholders wishing to access children's points of view and build their SD skills, especially in children who may have difficulties with writing and/or verbalizing their views.

Additionally, the school psychologist, while acting as liaison between all the stakeholders, should acknowledge and take into consideration the context of the family in their assessments, interpretations of results from the assessment and recommendations, and in any intervention they participate in. For example, in the current study, in speaking with the adoptive mother of Chris, Mack, and Adam, she shared that she was the biological grandmother of the children, and that their mother had another adult child who also had FASD who was not functioning very well independently. The three boys had been rated as the highest overall functioning on the ABAS-2 measure as compared to how other guardians had rated their children, and this grandmother's ratings were higher than boys' teachers' ratings. It is likely that the boys were lower functioning than she rated them as being. It is possible that she was comparing her boys to their older sibling who, comparatively, was faring worse than they were.

A respondent's frame of reference is important to identify and consider when working with any family, teacher, or other professional.

Research. Future school-based studies involving children and youth with FASD could be expanded to include analysis of whether the participants have individualized education plans, and if so, what is included within them. This information would further the understanding of what supports the child is already entitled to at school, and could provide triangulation of what the students, teachers and guardians report qualitatively. Deeper analysis would also dissect how the supports are being implemented and their effectiveness, how they are benefitting the child, and identify if there are any areas in which over-restriction may be occurring. Observation within the school setting would further the knowledge of the supports being implemented, and offer further triangulation on questionnaire data and other sources of qualitative information.

Research involving the FASD population should use a systemic PPCT framework. The complex political history and ongoing stigma related to the disorder is necessary to consider in working with families and the individuals effected by FASD. Neglecting to consider this impact on their lives is to negate sections of their experience. Further, the disorder is multi-faceted; the ways it impacts an individual are unique but pervasive. Increased knowledge of the disorder and how to help those effected can only meaningfully occur when the variables under study are placed in context. The interactions between variables should also be considered as these interactions influence a persons' development as significantly as individual variables do.

Further studies that involve SD skill, EF, and/or social skills training would add considerably to the current literature, particularly large-scale randomized control studies of which there are close to none. Idyllically, intervention-based studies focused on this population would be longitudinal in nature to investigate how improvements of the target area (e.g., EF or social skills) impact participant outcomes.

The use of visual means, including photographs and drawing, to elicit the views of children with FASD is encouraged. For example, the children's views regarding the intervention process and associated outcomes would further our understanding of how to implement these programs successfully. The perspectives of children with FASD would also be helpful in assessing the effectiveness of any treatment interventions. The views of children with FASD could also be explored in other settings and across time to further our understanding of their experiences.

Policy. Educational policy in Ontario does not currently recognize FASD as an exceptionality (Ministry of Education, 2017). Dependent on how the disorder is impacting the individual, children with FASD would likely fall under the categories of learning disability, behavioral exceptionality, or multiple exceptionalities. While it is positive that children are receiving services under these labels, the likelihood of the child with FASD receiving the full extent of support they need is lower without having a distinct category and the requisite distinct services that accompany such recognition. Within the same system, ASD is considered its own category of exceptionality (under the category of communication disorder), and as such, there are several types of specialized resources available for children who are identified with this disorder including teams of experts that travel to schools and specialized classrooms. Recognizing FASD as an exceptionality would help to address the specific needs of the population rather than lumping these children into catch-all categories. This recognition may reduce stigma by bringing the disorder to light. Adapted classroom environments would be available to the children who need them. The supportive adapted environments have been beneficial in other provinces such as Manitoba where recognition and knowledge of FASD within the education system is more explicit than in Ontario (Millar et al., 2017). Education policy makers could use the Manitoba model as a template in addressing the needs of children with FASD in schools in more overt and unambiguous manners.

In addition to the current hazy state of the Ontario educational policies regarding FASD, parents of children with FASD in Ontario have negative perceptions of how the legislation regarding their children with FASD is implemented in schools (Duquette et al., 2012). Specifically, parents felt uncertain if they would be meaningfully involved in decision-making, and were insecure regarding whether the appropriate programs would be provided to their child (Duquette et al., 2012). Parents of children with FASD thus have difficulty trusting schools to provide the services and support their child requires to be successful. They also learn from experience that attempts to collaborate can be met with either willing partners or resistance. Their first interactions with schools ultimately color their views and expectations for collaboration, and in turn will likely influence how they interact with school authority figures in future attempts. Therefore, a negative first experience can ultimately be quite detrimental to the child as persistence in high school for youth with FASD appears to be related to parent advocacy (Duquette et al., 2006a). School staff should thus make a conscious effort to welcome and support parents of children with FASD without judgment, particularly early-on in the child’s education. This awareness should be explicitly addressed in teacher-preparation courses and in teaching practicums. School administration should set the example to their staff of warmth, acceptance, and collaboration toward families who are involved in raising a child with FASD.

With regard to large-scale de-stigmatization, efforts to reduce public stigma have been successful by encouraging positive social contact (London & Evans-Lacko, 2010), and by deindividualizing disorder by bringing context into consideration (Rüsch, Kanter, & Brondino, 2009). Resilience to public stigma can be achieved through group membership (Corrigan, Kosyluk, & Rüsch, 2013). Group membership gives rise to a sense of community, perhaps an organization from which publications are sent whereby their collective voices, politics, and goals are established and discussed. Indeed, “members of a particular stigma category will have a tendency to come together into small social groups whose members all derive from the category, these groups themselves being subject to overarching organization to varying degrees” (Goffman, 1963, p. 23). However, while advocacy groups for the FASD population currently do exist, there may be lower than expected participation due to its strong stigma. Further efforts to expand membership in these groups and to have their influence gain a wider audience would work to counter both the stigma of the disorder as well as the effects of stigma on the individuals involved. Membership could be incentivized through government-organized subsidies and benefits such as provision of travel costs, organizational discretional funding, and streamlined access to FASD-specific human resources (e.g., connection to specialized psychologists, behavior therapists, case workers, medical doctors).

Concluding Comments

A goal of completing this dissertation was to give a voice to children with FASD regarding their school experiences, and to increase our understanding of SD in children with FASD using a PPCT framework. Several interesting and important findings were revealed, and several implications and suggestions for practice, research, and policy were discussed. Many of these findings and implications are unique and original contributions to the field, and I hope each finding served to honor the child participants’ voices. Several exciting and promising areas to focus on moving forward in research, policy and practice were brought forward, bringing optimism and hope to a population that has been historically plagued by stigma. With this study among others, children with FASD are brought out of the shadows. With improved supports and interventions, it is hoped they will grow to live in a self-determined manner free from undue restrictions.

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Appendix A

Recruitment Flyer

SEARCHING FOR:

Children aged 10-15 diagnosed with a Fetal Alcohol Spectrum Disorder (FASD)

WHY:

Research study looking at the development of skills for independent living and good decision-making in children with FASD to inform teachers, parents, and policy makers on how to best support these children.

WHAT:

Two short questionnaires for your child, two questionnaires for your child’s teacher, and three questionnaires for you. Also, your child will take some pictures of what they think they are great at and what they find difficult at school and she or he will discuss them with me.

HOW LONG:

One hour-long session with you and your child, and a 45 minute session with your child’s teacher

WHAT DO YOU GET:

Cash: $25. You will also get information on how to further support your child in developing independence and good decision-making skills.

WHO:

Marina Dupasquier: Doctoral candidate through McGill University
Supervised by Dr. Tara Flanagan
Contact me at fasdstudy@gmail.com or
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____

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Appendix B

Consent and Assent Forms

Dear Parent/Guardian, I, a doctoral candidate, am part of a research study group that aims to understand what skill set children with an FASD may have in making good academic and social choices in school (i.e., ‘self-determination’), and the different factors that can affect the child’s skill set. This is important information that can be used to advise parents, teachers, and administrators of what they can do to make education as successful as possible for children with an FASD.

I plan to do this through having your child take pictures and complete questionnaires. I will ask your child to take pictures of what she or he feels best at, and what is most difficult for him or her, in regard to their schooling. Your child will choose two of these pictures, one to represent each concept, and the child and I will have a brief discussion on what he or she intended to portray in the picture. I will ask you, your child, and your child’s main teacher to fill in a short questionnaire about self-determination, and for you and your child fill in another short questionnaire about your child’s quality of life. You and your child’s teacher will each be asked to complete a standardized questionnaire about how she or he gets along at home and school in terms of social, day-to-day living, and thinking skills. I will need to meet with you and your child once, and your child’s teacher once, each for about an hour. You and I will decide on a good location for the photography session as well as our sessions together, and I will coordinate with the teacher on the session with him or her.

The discussion of what your child finds difficult runs the risk of being uncomfortable for him or her. **You or your child can back out of the study at any time without consequence.** Your child’s participation has no effect on his or her grades in school, and s/he is not obligated to answer any questions s/he does not wish to. No information will be communicated to a third party (including staff at the school). All files will be confidential; codes instead of names on will be used on all materials and everything will be kept in a locked file in a locked office to which only my research supervisor and I will have access. Files will be shredded five years after the last contact I have with your child. The pictures I will use for my study will contain no faces or other identifying features of your child or his or her friends/school/ teacher. Only the pictures your child chose will ever be used in my research and all others will be deleted. You will be compensated $25 cash for your time and effort. There is no direct benefit to your child. Results will be provided through online access to the completed dissertation, a final report to the Fonds Quebec de Recherche Societe et Culture (FQRSC) funding agency, and academic conference presentations and publications. An informational pamphlet will be distributed to participants outlining the main findings of the study and how they can be applied in real-life situations.

I will break confidentiality if there are reasonable grounds to suspect child neglect or abuse, or if there is intent to cause serious and imminent harm to oneself or others. This will be reported to the relevant authorities such as the police or the youth protection authority. If you have any questions about this or any other aspect of the study, please contact me through the methods listed below. If you have any questions or concerns regarding your rights or welfare as a participant in this research study, please contact the McGill Ethics Officer at 514-398-6831 or lynda.mcneil@mcgill.ca. You are always free to ask me questions about this aspect of the study, as well.

Sincerely,
Marina S. Dupasquier, Ph.D. Candidate, McGill University
Tel: (***) ***-****. Email: marina.dupasquier@mail.mcgill.ca
Supervised by Dr. Tara Flanagan, McGill University
Tel: (514) 398-3441. Email: tara.flanagan@mcgill.ca

CONSENT FORM:

In signing this consent form, I recognize that the study has been explained to me, and that I understand the purpose of the study. I also agree that I have had the opportunity to ask questions about the study, and that all my questions have been answered satisfactorily.

I, ____, have read the above description. I fully understand the procedures, advantages and disadvantages of the study, which have been explained to me. I freely and voluntarily consent to participate in this study. I also consent to have my child ____________________ participate in the study.

Further, I give permission for the researcher to contact my child's main teacher _____________________ to request that he/she complete a short, standardized questionnaire about classroom behaviors and one short questionnaire about self-determination.

Name of child

Name of parent/guardian

Signature of parent/guardian

Date

McGill

Dear Teacher,

I, a doctoral candidate, am part of a research study group that aims to understand what skill set children with an FASD may have in making good academic and social choices in school (i.e., 'self-determination'), and the different factors that can affect the child's skill set. This is important information that can be used to advise parents, teachers, and administrators of what they can do to make education as successful as possible for children with an FASD.

In order to do this, the child, the child's guardian, and you - the child's main teacher - to fill in a short questionnaire about self-determination. You and the child's guardian will also be asked to complete a standardized questionnaire about how she or he gets along at home and school in terms of social, day-to-day living, and thinking skills. I will need no more than 60 minutes with you to discuss the study and to fill in the questionnaires; this can be done at your place of work or any other place you prefer. I will ask the child to take pictures of what she or he feels about school, specifically what she or he best at, and what is difficult for him or her. I will need to meet with the child and his or her guardian once for approximately an hour. All sessions with the child and the child's guardian are to take place outside the school property. Consent from the parent or guardian of the child has been granted (see attached form). Should you agree to participate, please know that **you may back out of the study at any time without consequences.**

No information will be communicated to a third party (including staff at the school). All files will be confidential; codes instead of names on will be used on all materials and everything will be kept in a locked file in a locked office to which only my research supervisor and I will have access. Files will be shredded five years after the last contact I have with the child. The pictures I will use for my study will contain no faces or other identifying features of the child or his or her friends/school/teacher. Only the pictures the child chose will ever be used in my research and all others will be deleted. Results will be provided through online access to the completed dissertation, a final report to the Fonds Quebec de Recherche Societe et Culture (FQRSC) funding agency, and academic conference presentations and publications. An informational pamphlet will be distributed to participants outlining the main findings of the study and how they can be applied in real-life situations

I will break confidentiality if there are reasonable grounds to suspect child neglect or abuse, or if there is intent to cause serious and imminent harm to oneself or others. This will be reported to the relevant authorities such as the police or the youth protection authority. If you have any questions about this or any other aspect of the study, please contact me through the methods listed below. If you have any questions or concerns regarding your rights or welfare as a participant in this research study, please contact the McGill Ethics Officer at 514-398-6831 or lynda.mcneil@mcgill.ca. You are always free to ask me questions about this aspect of the study, as well.

Sincerely,
Marina S. Dupasquier, Ph.D. Candidate, McGill University
Tel: (***) ***-****. Email: marina.dupasquier@mail.mcgill.ca
Supervised by Dr. Tara Flanagan, McGill University
Tel: (514) 398-3441. Email: tara.flanagan@mcgill.ca

CONSENT FORM:

In signing this consent form, I recognize that the study has been explained to me, and that I understand the purpose of the study. I also agree that I have had the opportunity to ask questions about the study, and that all my questions have been answered satisfactorily.

I, ____, have read the above description. I fully understand the procedures, advantages and disadvantages of the study, which have been explained to me. I freely and voluntarily consent to participate in this study.

Name of the participant

____

Signature of participant Date

McGill

I, ____________________________________understand that my parent/guardian has given permission (said it's okay) for me to take part in a project about how I feel at school done by Marina.

I have been told about all the different activities that are part of the study and that I might find some hard do to. I have also been told why it is good that I am doing these activities. I have been able to ask questions about the study and know I can ask more questions any time I like.

I am taking part because I want to. I have been told that I can stop at any time I want to and nothing will happen to me if I want to stop.

Signature: _______________________________________

Date:________________________________

McGill

Consent for Using My Photos:

I agree that the Ms. Dupasquier can use the photos I have taken. You can use it in any way that helps to educate about this study and its message. For instance, you can put it in a dissertation; in book chapters; on a website; in journals; use it at a conference presentation; use it at photo exhibitions to be held with community, school, church, not for profit, donors, government, academic, civil society groups etc.; use it at meetings with community, school, church, not for profit, donors, government, academic, civil society groups etc. You can give it to the media to publish. I have looked at my photos very carefully with my parent or guardian. We both feel that there is nothing that might cause me or anyone I know harm or embarrassment.

☐ Please give me credit with my full name at all times.

☐ Never give my name when you show this art.

☐ Please use my "pen name" to credit me.

☐ My pen name is:

____

Print name

____

Sign here

____

Date

The ideas for this form were taken from Claudia Mitchell et al.'s research entitled: Taking Action: Using Arts-Based Approaches To Develop Aboriginal Youth Leadership In HIV Prevention.

Appendix C

Participants' Demographic Information

Table 1C

Participant Demographics

Participant	Gender	Age	Grade	Diagnosis	Guardian Relationship	Teacher Title
Summer[a]	F	12	7	ARND	Adoptive Mother	-
Adam	M	11	6	ARND	Biological Grandmother	Homeroom
Mack	M	12	7	FAS	Biological Grandmother	Homeroom
Chris	M	14	9	FAS	Biological Grandmother	Special Education
Ethan	M	10	5	pFAS	Adoptive Mother	Special Education
Alex	M	11	7	ARND	Adoptive Mother	Special Education
Jack	M	14	9	FAS	Adoptive Mother	Special Education
Eva	F	12	7	pFAS	Adoptive Mother	Homeroom

Note. [a]Summer's guardian declined teacher involvement in the study.

Appendix D

Results and Descriptive Statistics from Questionnaire Responses

Table 1D

ABAS-2 General and Composite Scores

	GAC		Conceptual		Social		Practical	
Participant	Guardian	Teacher	Guardian	Teacher	Guardian	Teacher	Guardian	Teacher
Summer[a]	69	-	69	-	102	-	56	-
Adam	85	*57*	87	*50*	72	*68*	94	*67*
Mack	85	*74*	85	*67*	90	*90*	90	*70*
Chris	64	*56*	78	*59*	58	*72*	65	*55*
Ethan	63	*70*	57	*56*	78	*87*	62	*75*
Alex	62	*79*	70	*67*	64	*81*	50	*86*
Jack	68	*64*	70	*53*	92	*91*	58	*65*
Eva	67	*113*	72	*103*	87	*114*	56	*111*

Note. All scores are reported as standard scores. Teacher responses are italicized for ease of reading. GAC = General Adaptive Composite.

[a] Summer’s guardian declined teacher involvement in the study.

Table 2D

ABAS-2 Guardian Domain Scores

	Com	CU	FA	HL	HS	LS	SC	SDir	Soc
Summer	5	3	6	3	4	10	2	2	11
Adam	10	10	8	9	12	9	4	4	2
Mack	11	11	7	6	10	8	3	2	7
Chris	10	8	6	3	3	2	2	1	1
Ethan	3	3	3	2	9	8	1	1	3
Alex	7	5	6	1	3	5	2	1	2
Jack	7	6	4	3	2	7	2	3	9
Eva	6	3	6	3	3	11	3	3	3

Note. All scores are reported as scaled scores. Com = Community; CU = Community Use; FA = Functional Academics; HL = Home Living; HS = Health and Safety; LS = Leisure; SC = Self-Care; SDir = Self-Direction; Soc = Social.

Table 3D

ABAS-2 Teacher Domain Scores

	Com	CU	FA	SL	HS	LS	SC	SDir	Soc
Summer[a]	-	-	-	-	-	-	-	-	-
Adam	1	9	1	2	3	4	1	1	3
Mack	2	8	4	4	3	7	2	4	8
Chris	2	5	3	1	2	7	4	1	2
Ethan	5	11	1	1	3	7	8	1	8
Alex	4	10	4	1	3	9	11	2	3
Jack	1	2	2	1	1	9	11	1	7
Eva	11	11	11	11	11	11	10	9	12

Note. All scores are reported as standard scores. Com = Community; CU = Community Use; FA = Functional Academics; SL = School Living; HS = Health and Safety; LS = Leisure; SC = Self-Care; SDir = Self-Direction; Soc = Social.

[a] Summer’s guardian declined teacher involvement in the study.

Table 4D

ABAS-2 Average Scores Across Composites and Domains

	Guardian	*SD*	Teacher	*SD*
Community Use	6.50	*2.78*	7.71	*3.45*
Functional Academics	5.75	*1.48*	3.71	*3.19*
Home/School Life	3.88	*2.32*	3.00	*3.42*
Health and Safety	5.88	*3.79*	3.71	*3.06*
Leisure	7.50	*2.69*	7.71	*2.05*
Self-Care	2.38	*0.87*	6.71	*3.99*
Self-Direction	2.13	*1.05*	2.71	*2.76*
Social	4.88	*3.44*	6.14	*3.36*
Conceptual Composite	73.50	*9.04*	65.00	*16.64*
Social Composite	80.38	*14.07*	86.14	*13.99*
Practical Composite	66.38	*15.39*	75.57	*16.92*
GAC	70.38	*8.75*	73.29	*18.01*

Note. The scores are representative of standard scores. GAC = General Adaptive Composite. SD = Standard Deviation. Summer's guardian declined teacher involvement in the study, therefore the averages and standard deviation of the teacher responses are based on the remaining seven participants. Additionally, one student (Eva) received standard scores of at least 10 in all areas while others were scored considerably lower, inflating the standard deviations.

Table 5D

AIR Scores

	Total SD			Opportunity			Capacity		
	Guardian	Teacher	Self	Guardian	Teacher	Self	Guardian	Teacher	Self
Summer	73	-	90	82	-	85	57	-	95
Adam	68	*48*	60	75	*72*	63	53	*34*	55
Mack	57	*60*	66	67	*72*	68	43	*57*	65
Chris	54	*50*	70	67	*58*	78	27	*44*	63
Ethan	58	*55*	65	70	*73*	53	40	*46*	77
Alex	57	*59*	74	73	*82*	77	30	*44*	72
Jack[a]	68	-	80	75	-	77	53	*46*	83
Eva	68	*76*	86	73	*83*	90	57	*69*	82

Note. Teacher responses are italicized for ease of reading. Total scores are reported as a value out of 100.

[a] Jack's teacher declined to rate him on opportunities for SD in the home and thus his opportunity score and his total score could not be calculated.

Table 6D

AIR Averages and Standard Deviations by totals and subdomains

	Guardian		Teacher		Self	
	Average	*SD*	Average	*SD*	Average	*SD*
Capacity - Do	45.00	*11.15*	67	*58*	74.88	*9.71*
Capacity - Feel	-	-	-	-	73.00	*16.06*
Capacity - Knowledge	-	-	48.00	*11.01*	-	-
Capacity - Ability	-	-	46.14	*12.43*	-	-
Capacity - Perceive	-	-	50.43	*10.03*	-	-
Opportunity - School	69.25	*5.12*	77.71	*12.97*	67	*15.74*
Opportunity - Home	76.25	*9.74*	67.33	*15.57*	80.75	*11.56*
Capacity	45.00	*11.15*	48.57	*10.39*	74.00	*12.05*
Opportunity	72.75	*4.60*	73.33	*8.24*	73.88	*11.23*
Total Self-Determination	62.88	*6.64*	58	*9.16*	73.88	*9.96*

Note. SD = Standard Deviation. Standard Deviations are italicized for ease of reading.

Table 7D

KINDL-R Guardian Scores

	Physical	Emotional	Self-Esteem	Family	Social	School	*Total*
Summer	31	75	63	81	69	50	*46*
Adam	69	63	75	38	38	56	*56*
Mack	75	81	50	50	38	63	*59*
Chris	88	38	38	38	25	63	*48*
Ethan	31	75	63	63	69	50	*58*
Alex	88	63	50	56	50	44	*58*
Jack	75	56	75	63	63	63	*66*
Eva	69	63	56	75	75	44	*65*

Note. Scores are out of a possible 100.

Table 8D

KINDL-R Self-Report Scores

	Physical	Emotional	Self-Esteem	Family	Social	School	*Total*
Summer	12	31	0	50	75	13	*30*
Adam	63	88	50	69	69	13	*58*
Mack	88	56	69	50	44	94	*67*
Chris	94	81	63	63	63	69	*72*
Ethan	56	94	69	56	44	44	*60*
Alex	69	75	75	75	81	75	*75*
Jack	75	75	63	63	75	75	*70*
Eva	63	94	75	56	100	75	*77*

Note. Scores are out of a possible 100.

Table 9D

KINDL-R Averages and Standard Deviation of Total and Domain Scores

	Guardian	*SD*	Self	*SD*
Physical	65.63	*20.96*	64.84	*23.16*
Emotional	64.06	*12.79*	74.22	*19.87*
Self-Esteem	58.59	*12.08*	57.81	*23.12*
Family	57.81	*14.91*	60.16	*8.23*
Social	53.91	*18.21*	68.75	*17.68*
School	53.91	*7.62*	57.03	*28.72*
Total	57.03	*6.60*	63.80	*14.12*

Note. SD = Standard Deviation.

Appendix E

Adaptive Behavior Assessment System, Second Edition (Harrison & Oakland, 2008): Sub-Domain Descriptions

Communication: Communication skills were assessed by questions regarding both verbal and nonverbal skills, as well as modulating social interaction appropriately through reasonable communication ability.

Self-Direction: Items within the category tend to relate to the ability to inhibit responses, use working memory (capacity to hold and manipulate information in one's mind), and to shift set which is the facility in unconsciously switching attention between tasks (Edwards & Greenspan, 2010; Greenspan & Driscoll, 2016). These skill areas fall under the umbrella of the overall concept of executive functioning.

Leisure: Items evaluated how independently a child can organize and engage in their own leisure time. For example, the respondents were asked to rate the children on if they follow rules of games, participate with others in games without encouragement, try new games or activities to learn something new, or invites others to join in on an activity.

Social: Sample items related to the social domain include if a child seeks friendships within their age group, if they are able to keep a stable group of friends and if judgement is sound around choosing the group of friends, and if they are aware of and able to communicate emotions.

Community Use: This area assesses the child's ability to operate functionally in the community. For example, items relate to such skills as library usage, self-reliant navigation in the neighborhood and in both familiar and unfamiliar establishments such as restaurants or stores, and the ability to interact appropriately with others in service or health care positions.

Health and Safety: A child’s capacity to independently take care of their own safety and health were assessed through questions relating to, for example, if they would be able to alert an adult of illness, to care for a minor scrape, and to look both ways prior to crossing the street.

Self-Care: The children were rated on their ability to engage in basic hygiene practices and other self-care skills such as awareness of if their clothing is straightened after using the washroom or drinking a liquid without spilling.

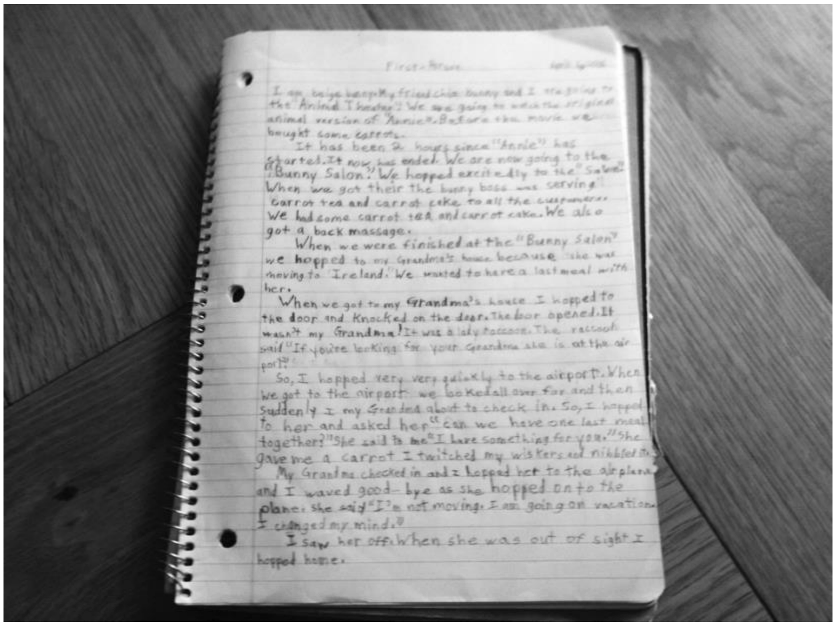
School/Home Living: The degree to which a child contributes and participates in the home or school was assessed. Items pertained to such behaviors as telling an adult if something is broken, showing respect for the rights and property of others, and keeping necessary daily supplies neat and in order (i.e., books, toys, toiletries).

Functional Academics: Skills such as basic reading, writing, and mathematics were assessed. More advanced skills such as taking notes during class, using resources to find information, or following a current event through news media were also evaluated.

Appendix F

Child Participants' Photographs

Figure 1F. Summer: Successful photo. Sampling of art made during art class.



I am beige bunny. My friend chloe bunny and I are going to the "Animal Theater". We are going to watch the original animal version of "Annie". Before the movie we bought some carrots.

It has been 2 hours since "Annie" has started. It now has ended. We are now going to the "Bunny Salon." We hopped excitedly to the "Salon." When we got their the bunny boss was serving " carrot tea and carrot cake to all the customers. We had some carrot tea and carrot cake. We also got a back massage.

When we were finished at the "Bunny Salon" we hopped to my Grandma's house because "she was moving to Ireland." We wanted to have a last meal with her.

When we got to my Grandma's house I hopped to the door and knocked on the door. The door opened. It wasn't my Grandma! It was a lady raccoon. The raccoon said "If you're looking for your Grandma she is at the air port."

So, I hopped very very quickly to the airport. When we got to the airport we looked all over for and then suddenly I my Grandma about to check in. So, I hopped to her and asked her "can we have one last meal together?" She said to me "I have something for you." She gave me a carrot I twitched my wiskers and nibbled it.

My Grandma checked in and I hopped her to the airplane and I waved good-bye as she hopped on to the plane. She said "I'm not moving. I am going on vacation. I changed my mind."

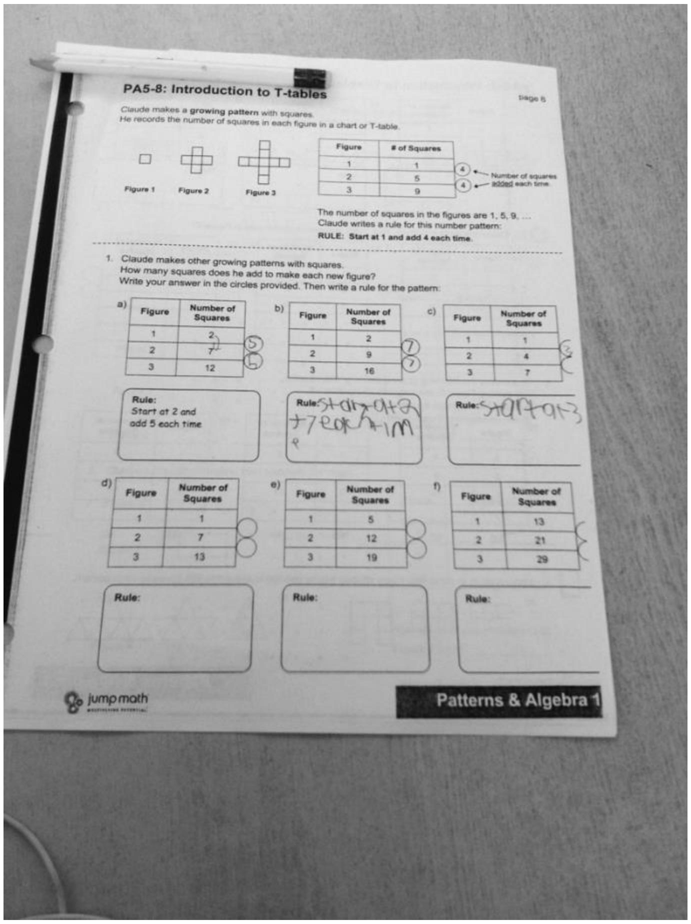
I saw her off. When she was out of sight I hopped home.

Figure 2F. Summer: Challenging photo. English language writing assignment.

Figure 3F. Adam: Successful photo. Hockey helmets kept in school gymnasium.

Figure 4F. Adam: Challenging photo. Mathematics problem.

Figure 5F. Mack: Successful photo. Science experiment equipment.



PA5-8: Introduction to T-tables

page 6

Claude makes a **growing pattern** with squares.
He records the number of squares in each figure in a chart or T-table.

Figure	# of Squares
1	1
2	5
3	9

④ ④ ← Number of squares added each time

The number of squares in the figures are 1, 5, 9, …
Claude writes a rule for this number pattern:
RULE: Start at 1 and add 4 each time.

1. Claude makes other growing patterns with squares.
How many squares does he add to make each new figure?
Write your answer in the circles provided. Then write a rule for the pattern:

a)

Figure	Number of Squares
1	2
2	7
3	12

⑤ ⑤

Rule:
Start at 2 and
add 5 each time

b)

Figure	Number of Squares
1	2
2	9
3	16

⑦ ⑦

Rule: Start at 2
+7 each time
e

c)

Figure	Number of Squares
1	1
2	4
3	7

3

Rule: Start at 1+3

d)

Figure	Number of Squares
1	1
2	7
3	13

Rule:

e)

Figure	Number of Squares
1	5
2	12
3	19

Rule:

f)

Figure	Number of Squares
1	13
2	21
3	29

Rule:

jump math

Patterns & Algebra 1

Figure 6F. Mack: Challenging photo. Mathematics worksheet.

Figure 7F. Chris: Successful photo. School gymnasium.

Figure 8F. Chris: Challenging photo. Geography classroom.

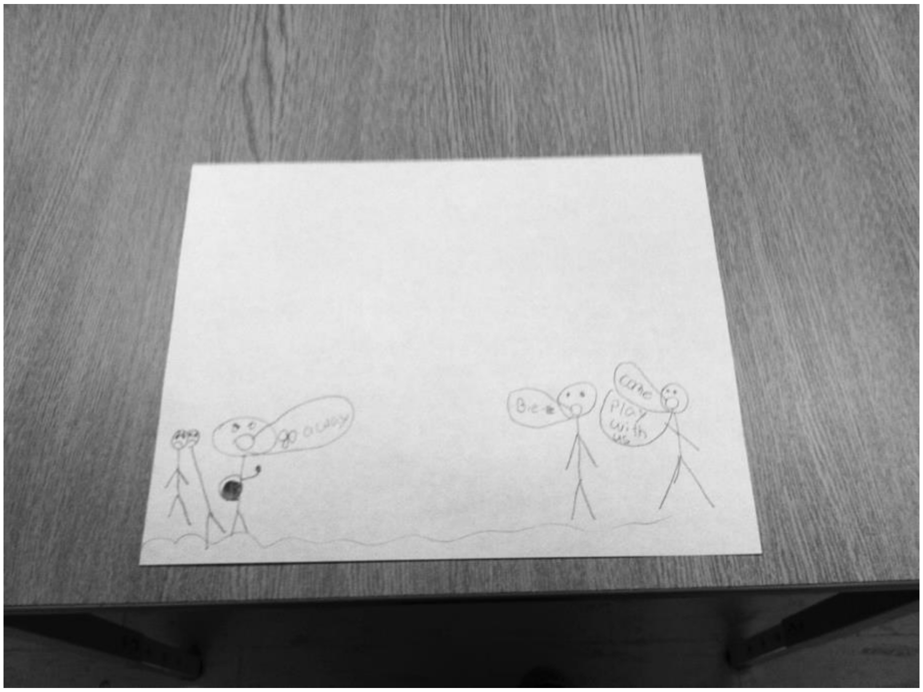
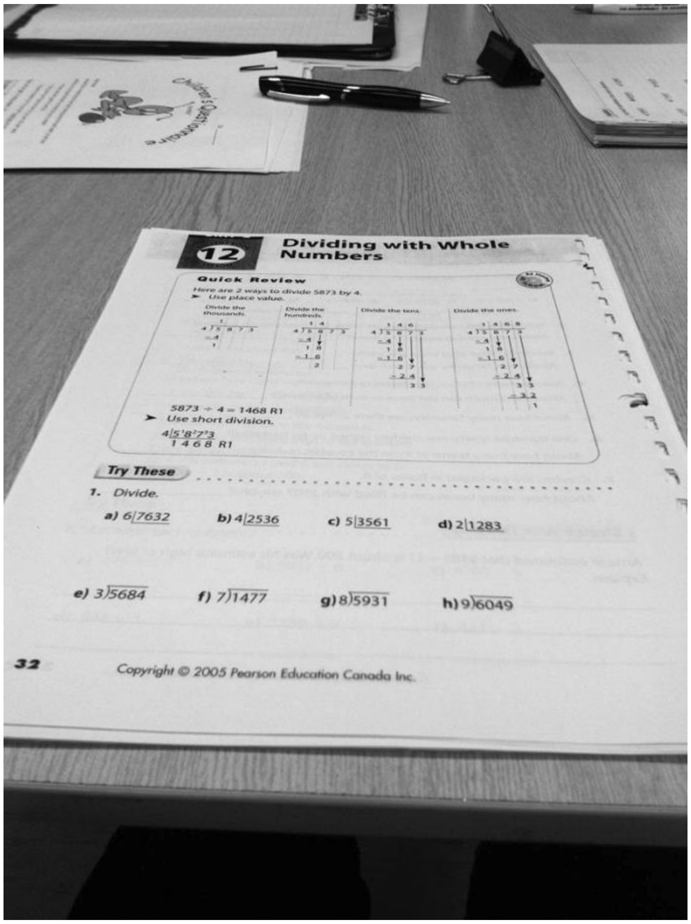


Figure 9F. Ethan: Successful photo. Participant's drawing of a calm reaction.



12 **Dividing with Whole Numbers**

Quick Review

Here are 2 ways to divide 5873 by 4.

➤ Use place value.

Divide the thousands. Divide the hundreds. Divide the tens. Divide the ones.

5873 ÷ 4 = 1468 R1

➤ Use short division.

$4\overline{)5^{1}8^{2}7^{3}3}$

1 4 6 8 R1

Try These

1. Divide.

a) $6\overline{)7632}$ b) $4\overline{)2536}$ c) $5\overline{)3561}$ d) $2\overline{)1283}$

e) $3\overline{)5684}$ f) $7\overline{)1477}$ g) $8\overline{)5931}$ h) $9\overline{)6049}$

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Figure 10F. Ethan: Challenging photo. Mathematics worksheet.

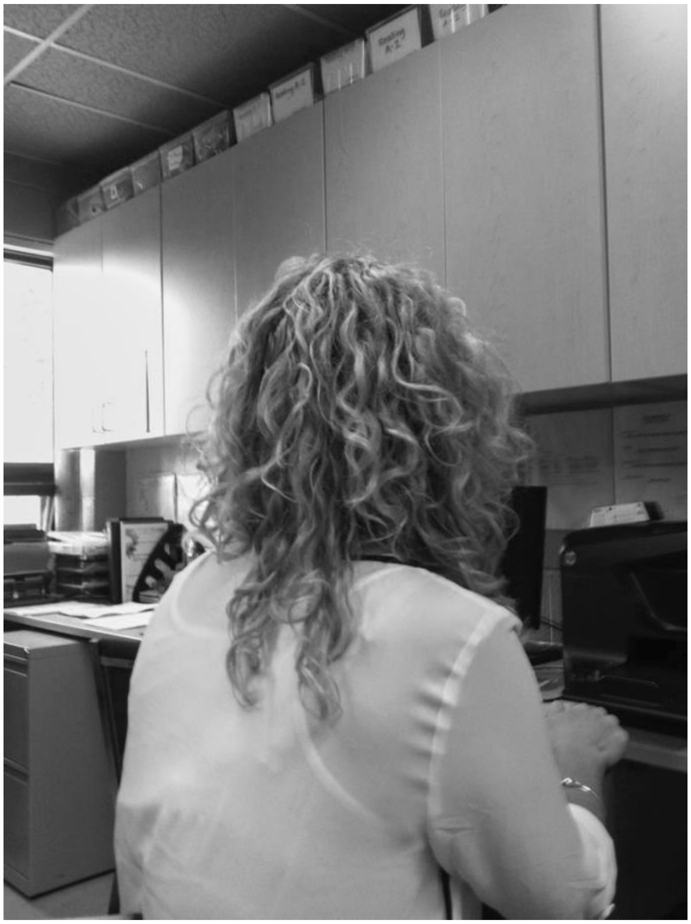
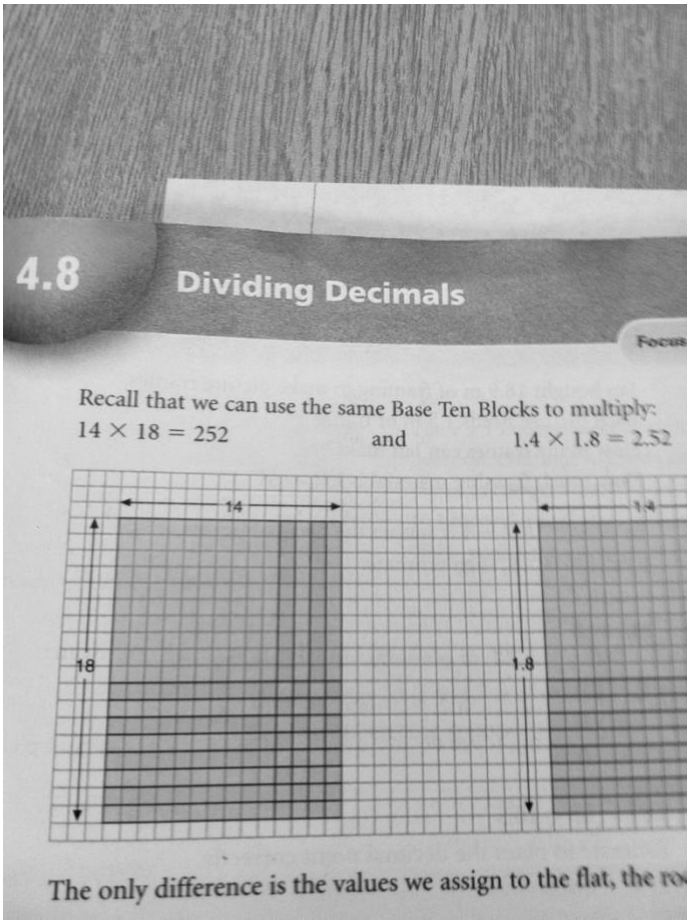


Figure 11F. Alex: Successful photo. Special education teacher (relationship with).



4.8 Dividing Decimals

Focus

Recall that we can use the same Base Ten Blocks to multiply:

14 × 18 = 252 and 1.4 × 1.8 = 2.52

The only difference is the values we assign to the flat, the ro

Figure 12F. Alex: Challenging photo. Mathematics textbook.

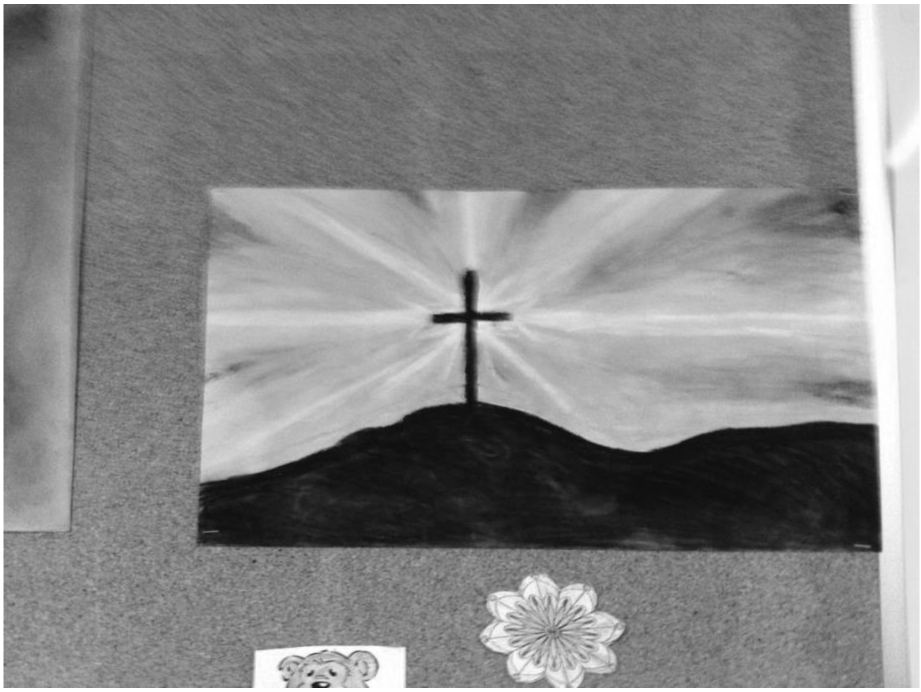
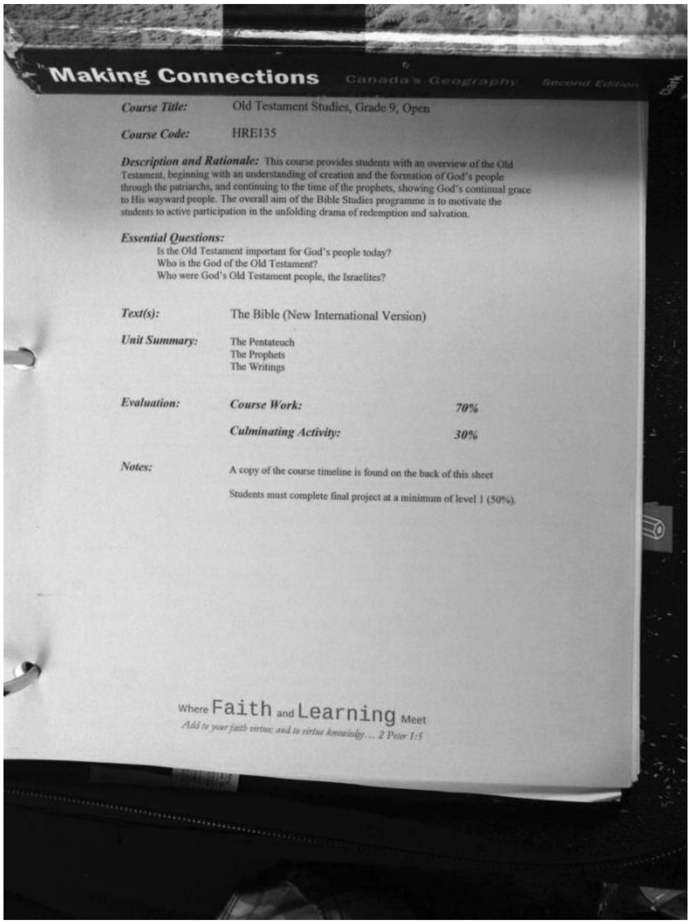


Figure 13F. Jack: Successful photo. Painting made as culminating project in art class.



Course Title: Old Testament Studies, Grade 9, Open

Course Code: HRE135

Description and Rationale: This course provides students with an overview of the Old Testament, beginning with an understanding of creation and the formation of God's people through the patriarchs, and continuing to the time of the prophets, showing God's continual grace to His wayward people. The overall aim of the Bible Studies programme is to motivate the students to active participation in the unfolding drama of redemption and salvation.

Essential Questions:
Is the Old Testament important for God's people today?
Who is the God of the Old Testament?
Who were God's Old Testament people, the Israelites?

Text(s): The Bible (New International Version)

Unit Summary:
The Pentateuch
The Prophets
The Writings

Evaluation:
Course Work: ***70%***
Culminating Activity: ***30%***

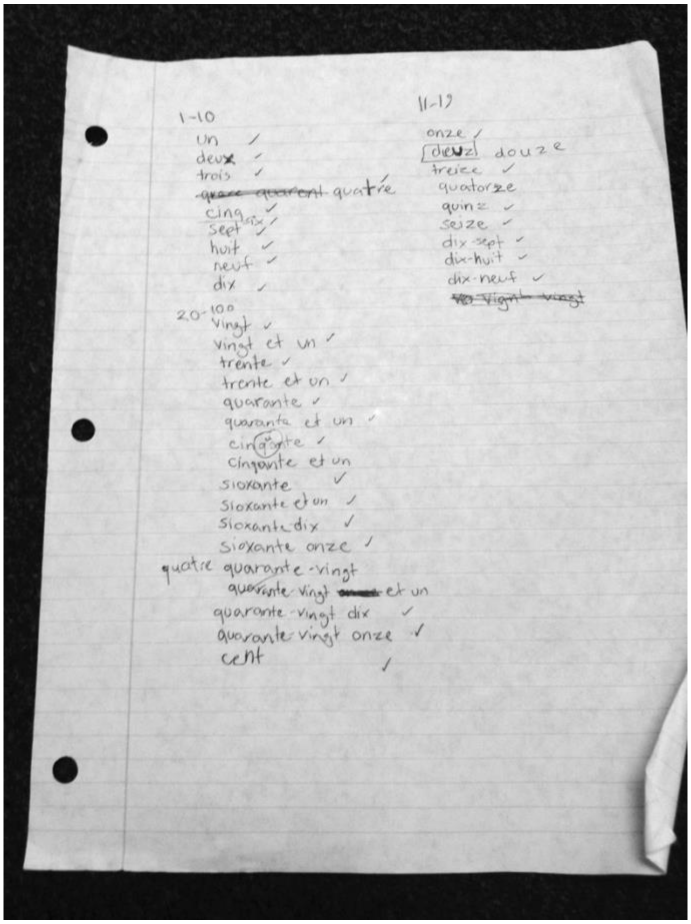
Notes:
A copy of the course timeline is found on the back of this sheet

Students must complete final project at a minimum of level 1 (50%).

Where Faith and Learning Meet
Add to your faith virtue; and to virtue knowledge… 2 Peter 1:5

Figure 14F. Jack: Challenging photo. Syllabus of religion class.

Figure 15F. Eva: Successful photo. Personal clarinet used in band and music classes.



1-10
Un ✓
deux ✓
trois ✓
~~quare quarent~~ quatre ✓
cinq ✓
six ✓
sept ✓
huit ✓
neuf ✓
dix ✓

20-100
Vingt ✓
vingt et un ✓
trente ✓
trente et un ✓
quarante ✓
quaranta et un ✓
cinqante ✓
cinqante et un
sioxante ✓
sioxante et un ✓
sioxante dix ✓
sioxante onze ✓
quatre quarante-vingt
quarante-vingt et un
quarante-vingt dix ✓
quarante-vingt onze ✓
cent ✓

11-19
onze ✓
dieuz douze
treize ✓
quatorze
quinz ✓
seize ✓
dix-sept ✓
dix-huit ✓
dix-neuf ✓
~~Vo Vignt vingt~~

Figure 16F. Eva: Challenging photo. French spelling test.