DAILY EXPERIENCES OF PARENTING A CHILD WITH SUSPECTED FASD AND THE APPLICABILITY OF A PSYCHO-EDUCATIONAL GROUP

by

Stephen David Robert Bennett

B.SC. University of Northern British Columbia, 2012

THESIS SUBMITTED IN PARTIAL FUFILLMENT OF
THE REQUIRMENTS FOR THE DEGREE OF
MASTER OF EDUCATION
IN
COUNSELLING

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

April 2015

Abstract

The present study explored the types of challenges parents with children of suspected FASD face on a daily basis and parents' experiences of those challenges. Participants were 7 foster and biological parents who were raising children with suspected FASD; these parents were scheduled to participate in a psycho-educational parenting group and their children were on a waitlist for assessment. Qualitative data was gathered using semi-structured interviews and journals. Data was analyzed using thematic analysis and incorporated aspects of the constant comparative method. Results suggest that participants have faced challenges related to a challenging environment, the child's impaired cognitive functioning, other medical conditions, seeking to facilitate the child's independence, and the child's confrontational attitudes. Meta themes included parents having hope that improvement was possible, parents' self-awareness and self-reflection, parents' flexibility and creativity, and parents' understanding of situations from the child's perspective. Implications for programming, counselling, and future research are discussed.

Table of Contents

Acknowledgements

I would like to thank all the parents for their time and willingness to share their daily experiences. Their insights and wisdom are invaluable.

I would like to thank SSHRC for supporting the research through the Joseph-Armand Bombardier Canada Graduate Scholarships Program Master's Scholarship

I also want to thank the health authority for their support of the research and funding for the psycho-educational group.

Thank you to my supervisor Dr. Corinne Koehn, and my committee members Dr. Cindy Hardy, Dr. Linda O'Neill, and Tammy Stubley.

Finally I want to thank all the transcriptionists who donated their time to assist with my research.

Dedication

This thesis is dedicated to my parents Joan Bennett and David Bennett. Without their love and support none of my accomplishments would have been possible.

I also owe so much to my friend and girlfriend Barbara Willmer. Her encouragement, sense of humour, and love is a tremendous gift.

Chapter One

Introduction

Fetal Alcohol Spectrum Disorder (FASD) has significant implications for the contemporary population, affecting approximately 1 out of every 100 children born each year in Canada (Chudley et al., 2005). Moreover, families caring for children with FASD must address the complex mental health and physical needs of their children on a daily basis (Brown, Sigvaldason, & Bednar, 2005). The various challenges faced by parents caring for a child with FASD highlight the importance for research that specifically examines the daily parenting of a child with FASD. Understanding of the challenges (e.g., compassion fatigue) faced by these parents has increased; this has prompted an examination of social supports that could assist families (Caley, Winkelman, & Mariano, 2009). Despite recent efforts (e.g., Shepard & O'Neill, 2012; Swart, 2012) to acquire and enhance an understanding of the rewards and challenges of parenting children with FASD, important aspects such as parenting a child with suspected but not yet diagnosed FASD, has yet to be examined.

A clear understanding of parenting a child with suspected FASD is essential because a formal diagnosis can take years to obtain and in some cases the condition remains undiagnosed because specific criteria cannot be satisfied (e.g., verification that the mother consumed alcohol during pregnancy; Ragsdale, 2006). Furthermore, parents caring for a child with disabilities often do not feel validated and supported by professionals, making the daily challenges they face that much more daunting (Brown et al., 2004; Green, 2007b). Even if professionals do acknowledge the challenges associated with suspected FASD, the vast majority of present services require a formal diagnosis before they can be accessed (Clarren, Olson, Clarren, & Astley, 2000; Streissguth & Giunta, 1988). Parents are left waiting for services while the absence of supports (e.g., psycho-educational groups) can perpetuate the development of additional challenges, also termed secondary disabilities (i.e., challenges that arise because of how FASD hinders people's ability to interact with the world around them; Boland, Chudley, & Grant, 2009; Duquette, Stodel, Fullarton, & Hagglund, 2006; Edmonds & Crichton, 2008; Sokol, Delaney-Black, & Nordstrom, 2003). These secondary disabilities can include mental health issues (Burd, Martsolf, Klug, & Kerbeshian, 2003; Famy, Streissguth, & Unis, 1998; Grant, Huggins, Connor, & Streissguth, 2005; O'Connor, Kogan, & Findlay, 2002; O'Malley & Storoz, 2003), poor school performance (Duquette & Stodel, 2005; Green, 2007a), legal problems, incarceration (Streissguth Barr, Kogan, & Bookstein, 1997), substance abuse (Baer, Sampson, Barr, Connor, & Streissguth, 2003; Famy et al., 1998; Streissguth et al., 2004), difficulty finding employment (Spohr, Willms, & Steinhausen, 2007; Streisguth et al., 1997), and challenges with living independently (Streissguth et al., 1997, 2004). The barriers to receiving a timely formal diagnosis combined with the possibility of additional secondary disabilities emphasizes a need to understand the daily parenting of a child with suspected FASD and specifically how parents experience the daily requirements of parenting.

Purpose of the Study and Research Questions

This study looked at the daily experiences of parents with children who have suspected FASD, providing invaluable insight into the human experience of parents whose children were on the waitlist for an FASD assessment. Specifically, the research attempted to address two interrelated research questions: (a) What types of challenges do parents of children with suspected but not yet diagnosed FASD face on a daily basis and how do parents experience those challenges? (b) In what ways can a support/psycho-educational group facilitate the parenting of children suspected to have FASD? The research was focused on the challenges of parenting because this information is needed to gain a clear understanding of what the content of the support/psycho-educational group should address. My thesis-based research attempted to fulfill two primary research objectives. First, the study provided insight into how families whose children have suspected FASD experienced parenting challenges on a daily basis. Second, the research inquired how this section of the FASD population utilized a support/psycho-educational group to facilitate parenting while waiting for a formal diagnosis.

This research may potentially benefit the academic community, professionals, and also the families who are coping with the daily challenges of parenting a child with suspected FASD. To the best of my knowledge, this is the first study focussing on the daily experiences of families with children who have suspected FASD, providing invaluable insight regarding the human experience of this section of the general population. The study's findings may also provide some direction with respect to improving counselling and other services available to parents whose child has suspected FASD. Moreover, this study helps raise critical questions about the unique challenges parents experience caring for a child with suspected FASD given the complex issues (e.g., physical and mental health) that they face. Furthermore, seeking to provide a timely interim service to parents has the potential to be cost effective and improve clients' quality of life. Efforts that reduce the severity of secondary disabilities could reduce the degree of services that children with suspected FASD will require over the course of their lives and facilitate their ability to live as independently as possible. This research provides an audience and validates the expert knowledge parents can offer in terms of the daily challenges of caring for a child with suspected FASD. Professionals should recognize the ongoing efforts of parents (Bryan, 2005) and seek to utilize the strengths and knowledge parents already possess (Galassi & Akos, 2007; Smith, 2006). This research not only informs future psycho-educational support groups for parents but also informs subsequent research into the experiences of families with children who have suspected FASD.

Location of Self in Research

I have an interest in working with children who have suspected FASD because of personal and professional reasons. On a personal level I have lived my life with a physical disability (i.e., very mild cerebral palsy). My parents experienced firsthand the challenges associated with acquiring a formal diagnosis and the unique challenges associated with the waiting period when a condition is only suspected. As such, I am keenly aware of the need for interim services to help with this period of concern and uncertainty. I believe that my background allows me to be sensitive to the challenges parents of children with suspected FASD face on a daily basis. I also know how important it is to respect the knowledge of parents since my family were the first ones to notice that something was not right when I was very young. They had to advocate for me and convince medical professionals to consider the possibility that a condition existed. Furthermore, this advocacy was ongoing since my parents' concerns were initially dismissed because medical professionals were convinced that nothing was wrong. On a professional level I see this research as being important to improving services for families in general and specifically in northern BC. Working as a counsellor in the north I will work with people who have various presentations of FASD. As such, I wanted not only to expand my knowledge of this condition but also to help contribute new knowledge and intervention strategies that can assist people with this condition to reduce secondary disabilities and live as productive a life as possible. I also want to create a foundation for a new area of FASD research that can be utilized by professionals. The goal is to help disseminate the invaluable knowledge and insights of parents to the professional community.

Conceptual Lens

I approached the research from a postmodern and constructivist perspective. I wanted to understand not only the daily experiences of parents caring for children with FASD but also how they interpreted and give meaning to these events. This is in keeping with the postmodern belief that what constitutes knowledge is subjective and that people's subjective interpretations of what events mean is vital (White & Epston, 1990). In honouring the knowledge and wisdom of parents I hope to empower participants by facilitating their efforts to be heard and understood by professionals. This desire to empower parents reflected the observation that power and knowledge tend to be linked with those who have authority trying to determine what constitutes knowledge (Foucault, 1979). I and others contend that the knowledge of parents is of equal value to the knowledge of medical professionals. Moreover, I endorse the constructivist contention that experiences should be viewed within a social context (e.g., social norms, institutions) to fully understand the situation (White & Epston, 1990; Winslade & Monk, 2007). Examining context was particularly important in terms of parenting children with suspected FASD since the availability of supports and services had the potential to impact parents' experiences. Finally, I sought to honour the experience (i.e., story) of parenting children with FASD (i.e., parents' experiences of suspected FASD). The belief that situations can be interpreted/constructed from multiple perspectives or stories is at the heart of a constructivist perspective (Madigan, 2011; White & Epston, 1990; Winslade & Monk, 2007). Using the lens of postmodernism and constructivism allowed me to approach the research with an open mind and understand the experiences of parents without imposing preconceptions (Winslade & Monk, 2007).

Articulation of Terms

Before the existing literature and methodology of the study can be considered, key terms must be clearly defined. FASD is an overarching term that describes the spectrum of symptoms that may be present when an individual's mother consumed alcohol during pregnancy. The symptoms can be diverse, and include physical, mental, behavioural and learning impairments (Chudley et al., 2005). The term, suspected but not yet diagnosed FASD, was used to describe children who were suspected of having FASD and had been placed on a waitlist with the Northern Health Assessment Network for a formal assessment. A parent was the person who was the primary caregiver for the child in question at the time of the study. As such, a parent could have been a biological, step, foster, or adoptive parent.

Overview of the Thesis

Chapter One has introduced the topic of study, specific research questions, articulates the justification for the study and situates the researcher within the study. Chapter Two provides a literature review of the existing FASD research. Chapter Three contains my chosen methodology. Chapter Four provides the findings of the study including categories and meta themes. Chapter Five discusses and reflects upon the findings, and includes implications for counselling, psycho-educational programming, and future research.

Chapter Two

Literature Review

A comprehensive literature search revealed no research focusing on suspected cases of FASD. Consequently, the literature review provided in this thesis is based on studies looking at diagnosed cases of FASD. Topics covered include the epidemiology of FASD, effects of prenatal alcohol exposure (PAE), the associated benefits/challenges of receiving an early FASD diagnosis, primary and secondary disabilities associated with FASD, needs of the family and caregivers, the importance of a northern context and existing parenting programs for families whose children have FASD. It is conceivable that dealing with suspected and diagnosed FASD will differ in some key areas (e.g., different types of challenges). However, understanding the research on diagnosed FASD places the research in context and provides a framework for understanding how suspected FASD represents a related but distinct research area. Moreover, 55.4% of children assessed by the Northern Health Assessment Network are found to have FASD (C. Wilson, personal communication, October 7, 2013).

Epidemiology

Before FASD can be properly considered, the epidemiology of FASD and PAE must be briefly examined. Current research suggests that prevalence rates are between 9 or 10 cases per every 1,000 live births, and therefore FASD is one of the primary developmental disabilities impacting children (Burstyn, Sithole, & Zwaigenbaum, 2010; Canadian FASD Research Network, 2014; Health Canada, 2002). Current Canadian statistics are based on prospective birth cohorts and data from the United States of America because epidemiological research in Canada is limited (Abel, 1995; Sampson et al., 1997). Moreover, some research suggests that the current prevalence rates could be low estimates due to methodological shortcomings in the American research (May & Gossage, 2001). In situations where the risk factors (e.g., low social economic status, binge drinking) are elevated, prevalence rates could increase to 19% (Robinson, Conry, & Conry, 1987). With higher rates of FASD associated with lower economic status, it is likely that the rates of FASD are higher in northern British Columbia relative to large urban centers (e.g., Vancouver). Generally speaking, social economic status tends to be lower in rural areas, relative to urban parts of Canada (Kulig & Williams, 2011). Moreover, it is conceivable that rates of suspected FASD are also higher in the north due to longer delays in receiving a formal diagnosis.

Risk Factors

An examination of the risk factors associated with FASD made it possible to get a preliminary understanding of the challenges faced by families who were likely to participate in the study. Generally speaking, families are at a higher risk for having a child with FASD when there is a history of insufficient nutrition, elevated stress, low social economic status, elevated levels of environmental pollution, drug use including tobacco, and a culture that endorses excessive alcohol consumption (Abel & Hannigan, 1995; Bingol et al., 1987; May et al., 2007). However, it is important to note that this is not a comprehensive or universal list. Families caring for a child with FASD may have only a few of these risk factors, other risk factors not outlined above, or none at all.

Formal Diagnosis

Following is a summary of proposed diagnostic criteria for FASD (Chudley et al., 2005). A complete list of the diagnostic criteria can be found in Appendix A. The general criteria for a diagnosis of FASD are evidence of impaired prenatal or postnatal growth, the congruent presence of three specific facial abnormalities at any age, impairment in three or more central nervous system areas, and confirmed (or unconfirmed) maternal alcohol exposure. The general criteria for a diagnosis of partial FASD are the congruent presence of two facial abnormalities at any age, impairment in three or more central nervous system areas, and confirmed maternal alcohol exposure. The general criteria for alcohol-related neurological developmental disorder are impairment in three or more central nervous system areas and confirmed maternal alcohol exposure.

It is important to note that the current diagnostic criteria for FASD are being refined. For example, researchers are focusing on facial features—specifically horizontal openings in the eye slits—and developing accurate Canadian normative data. Efforts are being made to develop a common set of tests that will be used to assess cognitive impairment so that the testing done at various clinics is standardized. Finally, attempts are being made to refine the diagnostic criteria associated with FASD so that it easily and accurately conveys the range of impairments that a particular person may or may not be experiencing (Canadian FASD Research Network, 2013).

Given the potentially high prevalence of suspected FASD in the north, the challenges associated with receiving a timely formal diagnosis becomes critical. Researchers have identified several factors that hinder efforts to receive a formal diagnosis, including the monetary cost of the assessment process and a shortage of clinicians with the training required to administer assessments. Within Canada most of the costs associated with the assessment are covered by the health care system. However, families sometimes incur costs when they have to travel to receive services. Moreover, the difficulties of receiving a timely diagnosis in childhood persist into adulthood (Chudley et al., 2005). Efforts to obtain a prompt diagnosis can also be hindered by an inability to obtain an accurate maternal history of alcohol consumption during pregnancy. Delays can compound the challenge of receiving an accurate diagnosis since the physical manifestations of FASD (e.g., eyelid slits), if there are any present, are most apparent between the ages of 2 and 11 (Ragsdale, 2006). A formal FASD diagnosis is complicated by the fact that each child presents with a compilation of symptoms that are unique to the individual in question (Malbin, 1993). The presentation of symptoms can vary depending on the child's stage of development (e.g., preschool or elementary school) and not all of the presenting symptoms may be related to the presence of FASD (Graefe, 1998; Harwood & Kleinfeld, 2002). The individualistic and somewhat fluid nature of FASD means that a comprehensive assessment is required to detect the presence of the disorder.

Unfortunately, the assessments used to facilitate a formal diagnosis can be problematic. For instance, the majority of school-based psycho-educational inventories assess academic strengths and deficits without properly gauging any neurological impairment associated with prenatal alcohol exposure (Blackburn, Carpenter, & Egerton, 2010; Connor, Sampson, Bookstein, Barr, & Streissguth, 2000; Steinhausen, Willms, & Spohr, 1993). In addition, current overall cognitive scores can fail to account for impairments in memory, attention and executive function associated with FASD (Kodituwakku, 2007; Streissguth, 1997). With the lack of understanding of FASD, the lack of properly trained clinicians, and the flaws inherent in some assessments, it becomes clear that parents often struggle to receive an assessment. The potential challenges inherent in receiving an assessment can be further complicated by the fact that not all assessment methods are capable of producing a reliable assessment. Although specialized tests that document neurological deficits in functioning (e.g., planning skills) do exist, research has indicated that accessing these resources may not always be possible (Green, 2007a). Ultimately, the inability to obtain a formal diagnosis places people in the category of suspected FASD which limits their ability to access services and supports that are available (Clarren et al., 2000; Streissguth & Giunta, 1988). Even when assessments have been performed, the majority of people on the FASD continuum do not meet the criteria for a formal diagnosis (Sokol et al., 2003). Importantly, the criteria for a diagnosis are not met despite the presence of cognitive, social, emotional, and behavioural problems linked to alcohol exposure (Coles, 2003).

Although receiving a diagnosis of FASD is challenging in general, receiving a prompt diagnosis in the north can be even more problematic. Northern communities are faced with a higher demand for formal diagnosis, restricted access to costly assessments, fewer services and supports, and a general lack of comprehension concerning the characteristics of FASD (Ollech, 2001; Ragsdale, 2006). Some studies examining rural communities in British Columbia have found prevalence rates of FASD as high as 19% (Robinson et al., 1987). Consequently, northern communities will likely be faced with far more suspected rather than confirmed cases of FASD. With the many challenges inherent in obtaining a formal diagnosis, research has highlighted the importance of providing more information regarding what parents can do to facilitate their child's cognitive and social skills. Helping parents to understand how they can support their child, though not a replacement for formal supports, is intended to empower parents and mediate secondary disabilities (Watson, Hays, Coons, & Redford-Paz, 2013). Taken together, the literature suggests that there is a considerable and continuous demand for services that target children with suspected FASD.

The challenges associated with receiving a formal FASD diagnosis notwithstanding, it is important to acknowledge that the province of British Columbia does have initiatives aimed at the prevention of FASD and the provision of assessment and support teams to assist families whose children have FASD. In Northern BC, the province has a dedicated assessment team (i.e., Northern Health Assessment Network's Complex Developmental Behavioural Conditions team) and key workers to facilitate the process of formal diagnosis and access to supports (Northern Health, 2011b). The Northern Health Assessment Network conducted approximately 234 assessments in 2011 (Northern Health, 2011a). The program recognizes that each family is distinct and the program may be accessed at any point without a referral from a medical professional (Government of BC, 2013). It is important to recognize that British Columbia is unique in its efforts to address FASD through the use of a dedicated assessment team (George & Hardy, 2013). Furthermore, the province runs annual awareness campaigns in an effort to educate the public about the dangers of prenatal alcohol exposure (e.g., annual BC liquor stores campaign; Government of BC, 2008). The province's existing efforts to address FASD made British Columbia an ideal location for examining the parenting of a child with suspected FASD. The province also has programs in place that offer support and access to care for at risk women while they are pregnant. These programs focus on ensuring that women have healthy pregnancies, hopefully preventing FASD and facilitating a positive parenting experience (Government of BC, 2008).

Primary and Secondary Disabilities

A comprehensive and timely diagnosis is essential for facilitating access to supports and services. Research has demonstrated that both formal diagnosis and implementation of services act as protective factors for children with FASD (Graefe, 1998; Streissguth Barr, Kogan, & Bookstein, 1996). Prompt detection of FASD and subsequent interventions can help to mediate associated primary and secondary disabilities (Swart, 2012). Primary disabilities are challenges resulting from the damage of the central nervous system associated with FASD. Conversely, secondary disabilities are impairments thought to arise from the primary disability and theoretically could be mediated or removed through better understanding and supports (Streissguth, 1997).

The primary disabilities associated with FASD can be diverse and pervasive. Research has demonstrated that alcohol exposure can cause vision and hearing problems (Burd, Cotsonas-Hassler, Martsolf, & Kerbeshian, 2003), scoliosis, epilepsy, urinary tract infections, congenital heart problems (Becker, War-leeper, & Leeper, 1990; Church & Kaltenbach, 1997), and impairments in motor control (Barr, Streissguth, Darby, & Sampson, 1990). School-based impairments have also been documented in memory retention (Kerns, Don, Mateer, & Streissguth, 1997), impaired speech and language (Timler, Olswang, & Coggins, 2005), poor adaptive functioning (Jirikovic, Olson, & Kartin, 2008), and behaviour problems (Burgess & Streissguth, 1990; Nanson & Hiscock, 1990; Streissguth et al., 1996). The various challenges experienced by children with FASD lead to disruptive behaviour both in the classroom and at home (Streissguth, 1997). Children are frequently unable to meet expectations, leading to secondary disabilities (e.g., defence mechanisms) which can be mediated with prompt and adequate supports (Malbin, 2002; Stressguth et al., 1996). These defence mechanisms can include behaviours such as becoming disengaged and indifferent towards completing tasks. The strengths (e.g., having aptitudes in areas such as experiential learning) that people with FASD possess can become diminished if they are not acknowledged and nurtured; children with suspected FASD may even lose interest in utilizing strengths if attempts to complete activities are frequently met with failure (Malbin, 2002). However, it is important to note that the link between primary and secondary disabilities remains unclear. A potential link between the two types of disability, however, is inconsequential since interventions can mediate secondary disabilities. The causal relationship does not need to be understood for interventions to be effective. The fact that adequate supports can prevent or reduce secondary disabilities speaks to the utility of offering supports to parents whose children have suspected FASD. Moreover, given that these secondary disabilities can arise relatively early (e.g., in elementary school) being proactive and offering supports prior to a formal diagnosis is vital.

Needs of the Family and Caregivers

When examining how to prevent secondary disabilities through interventions, there are several key challenges to consider. The challenge surrounding diagnosis is one of the major obstacles. In addition, the diverse supports sought by families and caregivers must also be acknowledged and accommodated if supports and services are to be effective. One of the most fundamental supports for families is a sense of being connected with people going through the same experience as a way to facilitate peer support through a common understanding (Shepard & O'Neill, 2012). A key experience for families is when healthcare providers value the vital knowledge of caregivers (e.g., parents) with respect to the challenges of people impacted by FASD. Doctors and nurses can learn about the challenges of FASD from the adults who have the disorder and their caregivers. Harriman (2007) suggests that adults with FASD and their caregivers are the "experts" with respect to the necessities of people with FASD. However, the invaluable knowledge of caregivers is often overlooked and devalued by health care professionals (Green, 2007b). In an effort to validate the knowledge and wisdom that caregivers possess, medical professionals need to engage in a collaborative relationship with parents. Input from caregivers, the community, and various organizations are critical in order to develop the additional supports that are required to meet the difficulties inherent in caring for someone with FASD (Bryan, 2005). Furthermore, collaborating with parents is an integral part of designing interventions for children with FASD, as doing so has implications for the effectiveness of treatment recommendations. Research has indicated that parental involvement is essential if the gains made during an intervention are going to generalize to everyday life (Hooper, Murphy, Devaney, & Hultman, 2000).

The many demands associated with raising a child with FASD places considerable strain on the family; therefore, adequate respite care for caregivers is vital (Shepard & O'Neill, 2012). Recent literature demonstrates that many of the hardships faced by caregivers are perpetuated by a lack of adequate environmental supports (e.g., Beckman, 2002; Worcester, Nesman, Mendez, & Keller, 2008). Adequate environmental supports have the potential to mediate the challenges faced by caregivers of children with FASD; it seems logical that adequate supports could also reduce the challenges associated with parenting a child with suspected FASD.

The findings of specific studies demonstrate the importance of working in collaboration with parents to determine their specific requirements and how best to meet their needs. Research has suggested that the challenges of parents are often misconstrued. For example, Green (2007b) found mothers of children with FASD were viewed by others as people coping with a profound tragedy and severe emotional distress. However, mothers of children with FASD indicated that they derive considerable love and pleasure from raising their children. Mothers reported difficulty coping with financial demands and time constraints (e.g., time required for medical treatments) rather than experiencing emotional distress. Parents' emotional distress may more likely emerge from the misconceptions held by the public and the struggle to access support services than from caring for a child with FASD (Green, 2007a). Green concludes that efforts to assist mothers of children with FASD may benefit from focusing on the financial and time demands rather than assuming that mothers are experiencing significant emotional distress.

Research by Shepard and O'Neill (2012) has also highlighted the financial strain faced by parents, along with parent requests for improved information, validation from health care providers, and the importance of community involvement as a way to facilitate the continued application of parenting skills learned during interventions. Parents indicated that they were unsure of what resources were available and how best to access the resources they knew existed. Furthermore, working with healthcare providers to access services raised the need for professionals to treat parents as equals rather than simply patients during the intervention. Parents also emphasized the benefits of community involvement (e.g., supportive professionals) as a way to help ensure that the gains made during the intervention were maintained in everyday life. To summarize, findings from these specific studies suggest an underlying theme of the importance of understanding what parents of children with FASD require rather than simply assuming that professionals intuitively know what supports parents need.

The challenges associated with parenting a child with suspected FASD may vary somewhat depending on the type of caregiver (e.g., biological or adoptive parent). Parents of children with FASD have indicated that they find going to conventional parent support groups problematic because they feel judged, stereotyped, and misunderstood (Shepard & O'Neill, 2012). Shepard and O'Neill (2012) suggest that it may be beneficial to provide separate groups for biological and foster parents as a way to prevent one group from judging the other. Having separate groups would also make it easier to target the specific requirements of each group. For example, Shepard and O'Neill's (2012) qualitative study involving 18 caregivers found that biological parents were more likely to be managing other conditions such as addiction. Birth parents also identified the fact that they did not have the same knowledge regarding access to resources as foster or adoptive parents.

There are some indications that foster parents may receive more supports than birth parents (Shepard & O'Neill, 2012). Assuming that these discrepancies are in fact present, birth parents may require additional support with advocating for adequate services and supports. Given that low economic status is a risk factor for FASD (Robinson et al., 1987), it is conceivable that birth parents may have fewer financial resources than adoptive or foster parents. As such, birth parents may require more comprehensive monetary assistance. However, it is important to note that financial hardship has been identified as a challenge by birth parents and adoptive parents (Shepard & O'Neill, 2012). Although there are commonalities between birth parents and adoptive/foster parents, each family also faces unique challenges that must be considered when designing effective interventions.

Some research describes the challenges parents of children with FASD may encounter in everyday life. For example, parents have revealed that they must constantly anticipate their child's behavior as a way to mediate potential problems, and that they must employ several different strategies for both inside and outside the home (Brown & Bednar, 2004). The effect of problematic behaviours can affect even simple daily activities such as eating (Brown & Bednar, 2004). Whitehurst (2012) found that children who have FASD can suffer from a projectile vomiting reflex; consequently, introducing solid foods can be a complex and slow process. Preventing problematic behaviour can be complicated by the fact that an effective strategy for one child may not be effective for another child (Brown & Bednar, 2004).

Adhering to schedules and making short or long term plans can be difficult for families with a child with FASD. For example, Brown and Bednar's (2004) qualitative study involving nine parents (i.e., adoptive, foster or biological) found that planning for and engaging in family outings were particularly difficult for parents since it was hard to predict how the child with FASD would behave. Despite the fact that planned family outings could be problematic, parents in their study also voiced concerns about social isolation and wanted to ensure that their child was involved in the community. Parents wanted their children to engage in social activities, such as school based activities, to help facilitate constructive interactions with peers of the same age. Whitehurst (2012) noted that children with FASD can struggle with interacting with other children; parents in the study commented that while in the playgroups their child with FASD would engage in odd behaviours (i.e., licking the furniture or spitting) that were not conducive to peer interactions.

Brown and Bednar (2004) emphasize that efforts to address parents' concerns require adequate supports. Parents in their study reported that professionals failed to validate their perspectives and provide the supports that they needed. Parents conceptualized the struggle to acquire supports as an ongoing battle of fear and anxiety, with birth parents also experiencing feelings of guilt. Similarly, Whitehurst (2012) observed that fighting for services placed parents in a situation in which they engaged in actions—such as subjecting their child to numerous assessments—that were inconsistent with instinctive parenting behaviour that would normally try to minimize a child's stress and discomfort, thereby placing an additional burden on parents. Moreover, making people aware of a child's FASD can perpetuate stereotypes and place parents on the defensive; adoptive parents have reported that disclosing that their child has FASD often perpetuates an explication that the child is adopted in order that parents can avoid being viewed as alcoholic (Whitehurst, 2012). In some respects, it seems that parents are confronted with a paradoxical situation of having the resolution of one challenge lead to another issue that must be addressed.

Brown and Bednar (2003) explored the types of resources sought by parents with children who have FASD. Parents indicated that they benefited from having supportive friends and family which included having a supportive spouse, siblings that provided help, and having contact with other parents who also cared for children with FASD and understood the inherent challenges. Consistent with other literature on FASD, parents spoke about the benefits of having supportive professionals. However, in this study parents also mentioned that it would be helpful to have access to a computer in order to locate resources and educational computer programs for their children. Parents expressed a desire for a school system that was inclusive and would work collaboratively with them to meet the requirements of their children. Early interventions and individualized education programs were identified as indicative of a supportive school system. Parents also alluded to the benefits of inclusive health and social services that provided financial support and medical supplies. Importantly, parents wanted services that they could access on their own and were flexible to accommodate each family's unique situation and existing resources. In terms of child management, parents identified qualities that could be effective when interacting with their children, such as flexibility, a sense of hope, and the ability to listen. Furthermore, parents recognized that certain personality traits, such as a sense of humour and the ability to remain patient and confident, were advantageous. Although the challenges identified in the study help elucidate what type of assistance may benefit parents of children with FASD, it is important to remember that the requirements of each child and family will be unique, making the customization of services important.

Paley, O'Connor, Frankel, and Marquardt (2006) examined aspects of parenting a child with FASD and found that problematic behaviour is associated with increased levels of parental stress. Children's externalizing behaviours (e.g., being overly active) and internalizing behaviours (e.g., being withdrawn or anxious) contributed independently to parents' stress. This suggests that parents were not only distressed by their child's disruptive behaviour but also by behaviour that might contribute to their child developing a mood disorder. Furthermore, parents found deficits in their child's executive function (e.g., cognitive skills) to be the most stressful, although the child's IQ appeared to have no bearing on parents' stress level. The authors suggest that parents were less concerned with general cognitive impairment and were more concerned with their child's ability to carry out tasks required for daily living (e.g., planning and problem solving). Assuming that these conclusions are accurate, interventions that target the skills essential for daily living could facilitate a dramatic reduction in the stress experienced by parents of children with FASD. Another finding was that there were differences in the level of stress experienced by adoptive/foster parents as compared to biological parents, even after controlling for the child's characteristics (e.g., behaviour). The authors suggest that one explanation for this discrepancy was that adoptive/foster parents may not have been properly informed about what to expect when caring for a child who has FASD. In addition, certain parental characteristics contributed to stress; biological parents with few financial resources experienced more stress relative to adoptive/foster parents with more financial resources. Moreover, the study revealed that the severity of the FASD diagnosis (e.g., FAS or partial FAS) had no impact on the stress experienced by parents. The authors maintain that services and supports should be offered to all parents caring for a child who has suffered the effects of alcohol exposure and not just the children who meet the criteria for a diagnosis of FASD, supporting the argument for the provision of services for parents whose children have suspected FASD.

Research has assessed ways in which nursing interventions could assist parents caring for children with FASD (Caley et al., 2009). Using a nursing classification system facilitated the identification of parents' concerns related to communication with community, caretaking/parenting, mental health and income. Signs and symptoms of problems relating to communication with community included professionals not having the necessary knowledge about FASD, a lack of awareness regarding the physiological mechanisms behind problematic behaviour, and health care providers missing the signs of FASD in young children. The most prominent item associated with parenting/caretaking was ensuring physical care/safety (e.g., immobilizing a child that is larger than the parent). Identifying signs and symptoms associated with mental health issues proved problematic for parents as it generated fear and apprehension about whether children could live independently, and the central role of a support system after family members passed away. Finally, parents had several concerns related to the monetary cost of raising a child with FASD. These concerns involved the cumulative cost of raising a child, guardianship, and medical costs that were not covered by health plans. Two additional concerns raised by some participants were the strain that raising a child with FASD had placed on their marriage, and the need for parents to also act as a teacher for the child. Given the complexity of caring for a child with FASD, having interventions initiated and implemented by health care professionals (i.e., nurses) could help provide additional supports and services for families.

Parents who themselves have FASD encounter unique challenges. Denys, Rasmussen, and Henneveld (2011) looked at the utility of a one-on-one mentoring program for parents with FASD, as a way to help parents meet their challenges and achieve goals that they set for themselves. In terms of parents' required supports, instances of abuse decreased the most over the course of the program, with the lack of access to social programs, housing and transportation and community resources showing the second highest decrease. These findings are relevant in that they address many of the challenges that parents with FASD face on a day to day basis. Interestingly, improving family parenting skills was the most common resource indicated by parents. However, parents made little progress in addressing parenting skills over the course of the mentoring program. The lack of progress with respect to parenting skills was attributed to the fact that many families were more concerned with meeting basic necessities such as food and housing. Although parents wanted to improve their parenting skills, the authors note that the stability of the family had to be established before parenting could be addressed. These findings suggest that interventions may have to promote family stability before parenting training can be facilitated, irrespective of parents' willingness to implement new parenting strategies. In addition, interventions for parents with FASD may benefit from addressing comorbid conditions (e.g., other mental health issues such as ADD or addiction; Denys et al., 2011). Finally, the study noted that parents with a formal FASD diagnosis showed greater reduction in their needs after the program, relative to parents who lacked a formal FASD diagnosis. Denys et al. suggest that this discrepancy may have been due to the fact that parents with a formal diagnosis had access to more support services and financial assistance. The differences in intervention outcomes associated with FASD diagnosis may support the argument to offer interventions that specifically target people who have suspected but not yet diagnosed FASD.

The experience of parenting with FASD was also examined by Rutman and Van Bibber (2010) who used a qualitative study with 59 people (i.e., 15 adults with FASD, 8 support people who worked with the adults, 36 multi-disciplinary service providers) to uncover several themes associated with parenting when the caregiver has FASD . Parents indicated a strong desire to see their children become decent people with a life that was "better" than that of their parents. Related to this desire for a better life were parents' efforts to end the cycle of FASD (e.g., presence of drinking or drug use; Rutman & Van Bibber, 2010). Parents' strong desire to improve their childrens' lives and put an end to the cycle of FASD seemed to suggest that at least some parents would welcome supports that are sensitive to their unique situation and intended to facilitate improvements in parenting. Indeed, parents in this study expressed a strong focus on accomplishments. These accomplishments were diverse and included having parents retain custody of their child or having their child returned to their care, finding ways to reduce drug use, and developing new strategies for self-regulation and better parenting However, despite the emphasis on progress and goals, parents identified several obstacles. Although having FASD presented challenges, many of the barriers parents identified were not directly related to their FASD but rather to secondary effects of the disorder (e.g., drug abuse). These secondary challenges included a lack of positive role models, poverty, ineffective welfare policies, and social stereotypes. The absence of adaptive role models was seen as especially problematic because parents lacked a concrete conceptualization of healthy parenting. For them, maladaptive parenting behaviours, although seen as detrimental, were normal because they had never experienced anything else. Providing parents with a concreate idea of what adaptive parenting looks like and how to implement parenting skills may provide a clearer picture of what these parents hope to achieve, facilitating their desire to work towards various accomplishments (Rutman & Van Bibber, 2010).

Rutman and Van Bibber (2010) found that parents with FASD articulated a strong history of abuse (e.g., emotional, physical, etc.) and an increased risk of victimization because their FASD impaired their ability to judge the trustworthiness of people. Parents with FASD were confronted with the challenge of addressing their own history of abuse and the difficulty in gauging social situations while also seeking to ensure the safety of their children. Parents found themselves caught in a paradoxical situation. On the one hand, many felt that their parenting was being dissected for any signs of failure and their strengths (e.g., perseverance and a desire to achieve goals) were discounted. At other times, because FASD is not always apparent, their need for supports was either not recognized or ignored and their present skills overestimated. Either extreme could place the parent at risk of appearing like an inept caregiver, thus negating their efforts to raise well-adjusted children. Finally, parents identified problems with the current policies surrounding social supports. Services such as respite care were difficult to access unless the family had already been investigated by child protection services and/or was in danger of having the children apprehended. Many other services (e.g., community living) were only available to people with FASD and who fell within a given IQ range. Parents commented on the fact that they felt that it was easier for foster parents to access resources such as financial supports. A lack of services may prevent parents with FASD from being able to parent their children effectively, necessitating outside interventions such as foster care.

Qualitative research by Michaud and Temple (2013), involving five parents of children with FASD, assessed parents' experiences of caring for a child with FASD and what families required to help ensure that children did not develop secondary disabilities. Parents explained that their previous experience with raising children was insufficient; when parenting a child who has FASD, it is necessary to change the environment to support the child rather than change the child to fit the environment. Implementing changes to accommodate the child rather than expecting the child to change is consistent with other research (Buxton, 2004; Dorris, 1989; Malbin, 2007). Although parents wanted to see their children become as independent as possible, parents were unsure of how to make the transition from caring for the child to helping the child achieve independence. Parents' concerns were related to the child not asking for help when it would be beneficial to do so, and the possibility of damaging the parent-child relationship if parents were too hyper vigilant. In other situations, parents felt guilty for asking the child to leave the family home because of aggressive behaviour. There was a sense of failure when parents were unable to continue raising the child. Moreover, parents were concerned about their child's future and the realization that certain developmental milestones may not be achievable. However, concerns about the future did not diminish the joy and gratitude parents derived from raising their children. Parents maintained a sense of possibility that with the appropriate resources their children could have rewarding lives. However, the uncertainty around being able to provide lifelong care for the child perpetuated ongoing emotional distress. Parents stressed the importance of more comprehensive supports and proper continuity of care as their children transitioned into adult life. A major worry for parents was that their children would not receive services as an adult.

Similarly, other research has indicated that parents whose children have FASD experience significant uncertainty about the future (e.g., Gardner, 2000; Olson, Oti, Gelo, & Beck 2009; Salmon, 2007; Sanders & Buck, 2010). Studies have found that parents have to contend with the realization that their role as caregiver is likely to persist throughout their child's life (Olson et al., 2009; Sanders & Buck, 2010). Gardner (2000) found that foster parents worried about their child being manipulated by peers and placed in unsafe situations. Salmon (2007) found that biological parents expressed grave concerns related to the challenges that could be created by their child's lack of social skills (e.g., lack of employment & incarceration). Watson et al. (2013) found that parents of children with FASD had hope that improvements were possible. However, parents of children with FASD had less hope than parents of children with autism. This discrepancy in parents' hope may be related to the fact that fewer effective treatments are available for FASD, and parents' perceptions that it would be easier for a person with autism to eventually be fully independent. Parents of children with FASD may experience more stress than parents caring for children with other cognitive impairments (i.e. autism), highlighting the importance of offering supports that specifically target the needs of families whose children have suspected FASD.

Zabotka's (2013) qualitative study, involving 11 biological mothers, examined the contextual factors that can contribute to drinking during pregnancy and biological parents' experiences of coping with the realization that their drinking caused their child's FASD. Almost all 11 parents experienced some form of childhood trauma in their lives (e.g., physical abuse, psychological abuse, etc.). Research has noted a relationship between childhood trauma and problems related to alcohol during adulthood (Miller, Downs, Gondoli, & Keil, 1987; Waldrop, Santa Ana, Saladin, McRae, & Brady, 2007; Widom & Hiller-Sturmhofel, 2001; Widom, Ireland, & Glynn, 1995; Wilsnack, Vogeltanz, Klassen, & Harris, 1997). Importantly, witnessing domestic violence may also contribute to problematic drinking later in life (Dube, Anda, Felitti, Edwards, & Williamson, 2002; Zabotka, 2013). Zabotka found that several participants experienced a sense of loss because at least one parent was physically or emotionally unavailable, which impacted the development of important skills such as problem solving. Furthermore, biological parents worried that they also had FASD and that this undiagnosed condition impacted their ability to parent effectively.

Zabotka (2013) noted that parents experienced intense guilt over the realization that their drinking caused their child's FASD. Importantly, these feelings of guilt persisted to some extent regardless of mitigating factors such as coping skills or having access to supports. Some parents did experience a concurrent sense of relief when a formal diagnosis was given. The diagnosis helped parents understand their child's actions and facilitated efforts to start accessing services for their child. Parents also sought to make sense of their drinking during pregnancy as a way to mitigate but not remove their guilt. Some parents used the disease model (Jellinek, 1960), which suggests that consuming alcohol is not something a person can control, as a way to explain their actions. When the disease is seen as causing the consumption of alcohol, then the person can shift a portion of guilt onto the disease, making it easier to cope. Other parents engaged in harm reduction (i.e., in which a person drinks less in an effort to decrease the risk to their unborn child; Zabotka 2013) which is consistent with the theory of cognitive dissonance. According to cognitive dissonance theory, people experience distress when their beliefs and actions are inconsistent (Festinger, 1962). By reducing their drinking, parents changed their actions and consequently reduced their distress. In some cases parents explained that they did not have an understanding of the dangers drinking posed to their unborn child. Zabotka noted that at times a lack of knowledge was perpetuated by inaccurate information or advice from friends, family, and in a few cases physicians. Parents merged the lack of knowledge with the disease model, explaining that the impact of the disease and incorrect information made it very difficult not to drink—an explanation that served to reduce but not remove feelings of guilt. At times, parents used denial to minimize the risks of drinking and ultimately lower their cognitive dissonance.

Zabotka (2013) explored the coping strategies of parents whose children had FASD. Almost all parents utilized some form of spirituality, although often not in terms of an organized religion, to make sense of their situation. Some parents focused on the positive and one parent explained that the birth of their child was the change in her life that stopped the drinking. This parent felt she could not drink anymore because her child now relied on her for care. The majority of parents also spent time on community causes and giving back to the community. Parents found that engaging in community causes was an ideal way to move forward; although past mistakes could not be undone, there was the possibility of helping someone in the future. Parents also coped by remembering that their children required support—focusing on helping their children as much as possible gave parents a sense of purpose. In an effort to help their children, parents sought additional support from friends and family. Unfortunately, not all parents had outside supports. Some parents felt judged and criticised for having a child with FASD. These negative experiences left parents with the impression that they could not rely on anyone except themselves. Finding ways to help parents cope and move forward appeared to be important mechanisms for making the feelings of guilt manageable.

Nash (2014) assessed the sensitivity of mother-child interactions when the infant has FASD. He examined how parents played with their child and then how parent and child interacted after the child had been exposed to a stressor (i.e., the parent would stop engaging with the child and give no facial responses for a period of time). Mothers of children with FASD demonstrated an ability to engage with the child in positive ways (i.e., maintain eye contact). However, parents found it challenging to read certain aspects of their child's behaviour (e.g., subtle cues). Importantly mothers of children with FASD did not differ in in the number of positive engagements with the child (e.g., a full smile) relative to mothers whose children did not have FASD. This finding, although encouraging, contradicts other research that found fewer positive engagements between the mother and child when the child has FASD (e.g., Eiden, Peterson, & Coleman, 1999; Eiden, 2001). One plausible explanation for this discrepancy could be that parents, fearful of being judged, intentionally tried to demonstrate what they thought was expected. During the reunion phase parents of children with FASD displayed fewer instances of social monitoring without vocal cues and more non-infant focused engagement (e.g., looking at things in the environment that don't relate to engaging with the infant). More frequent non-infant focused engagement is problematic since looking at the infant facilitated picking up on subtle cues. In addition, mothers of children with FASD exhibited less intense sensitivity (e.g., positive affect, acknowledging, supporting, etc.) during both the play and reunion phases. Parents of children with FASD may have found it more difficult to interpret subtle cues from the infant relative to the more overt distress cues that tended to happen during the reunion phase. Positive mother-child interactions facilitate development in all areas. Consequently, it may be beneficial to help parents develop tools for interpreting and responding to the subtle cues that their infants use to communicate (Nash, 2014).

Given the prominent role that foster parents can play in caring for children with FASD, the motives that underlie peoples' decision to foster a child with FASD should be considered. Brown, Sigvaldason and Bednar's (2007) qualitative study, involving 63 foster parents, found that the motives of licenced foster parents were in fact quite diverse. In some instances foster parents had a desire to facilitate positive change by helping children develop new strategies for dealing with their disability. Parents motivated by positive change derived satisfaction from aspects such as the child's achievements and seeing the child grow up. Foster parents were also driven by a desire to make a positive contribution to society with "rescuing" a child despite the many challenges and barriers the foster parents may encounter. Parents wishing to make a positive contribution focused on realizations such as knowing that they could take on a responsibility that others found difficult, and a desire to see the positive characteristics in children with FASD. Furthermore, some foster parents identified a desire for the parenting experience, feeling that they had both skills to provide and information to learn by fostering a child with FASD. People focusing on the parenting experience identified key motivations such as having been a parent for years and having attended workshops on FASD. Other motivating factors were a sense of obligation because there was a need for foster parents, and a desire to earn an income by working at home. People acting out of a sense of obligation focused on aspects that included using fostering as a source of paid employment and a desire to fill a need with knowing the child's parent had died. Other people decided to foster children with FASD because they felt confident in their abilities as parents and had learned a lot about parenting kids with disabilities. People with confidence in their abilities focused on skills such as knowing a lot about FASD and having a desire to learn about the needs of their child. Moreover, some foster parents took on the responsibility of caring for a child with FASD out of a desire to ensure that children stayed connected to their families and communities, and did not move from one foster home to another. Although the study noted that there are several similarities between foster parents who care for children with disabilities in general and those who care for children with FASD, there were also some important differences. Foster parents of children with FASD had a desire to be connected to various community supports, were committed to ongoing education, supported long term planning, and welcomed the involvement of other family members, including people from the child's birth family (Brown et al., 2007).

Other research has assessed how to reduce the number of foster care placements for children with FASD (Pelech, Badry, & Daoust, 2013). Having FASD is associated with frequent foster home placement changes (Habbick, Nanson, Snyder, Casey, & Schulman, 1995). Furthermore, there appears to be a positive correlation between frequent placement changes and subsequent negative outcomes for the child (e.g., school difficulties; Streissguth & Kanter, 1997). Pelech et al. (2013) found that a particular set of approaches, known as Promising Practices, facilitated increased placement stability for children with FASD. Caseworkers' understanding of the child's unique need increased when government ministry staff had more direct contact with the families. Foster parents found that consistent contact with the caseworker at least once a month facilitated not only a more positive relationship between the child and the caseworker but also a more positive relationship between the foster parents and the caseworker. Foster parents found that more consistent in person contact with the caseworker (i.e., home visits) allowed caseworkers to comprehend the home environment, the family's experiences, and the daily challenges associated with caring for a child who had FASD. Increased contact with the government ministry of family services enhanced foster parents' feelings of teamwork. The Promising Practices Program suggests that changes at the government level can play an important role in promoting the stability of foster placements (Pelech et al, 2013).

Northern Context

The role of a northern context in parenting a child with suspected FASD requires special consideration. Although FASD is by no means unique to Aboriginal communities, the disorder has had a pervasive impact on northern Aboriginal communities in BC. However, Aboriginal communities have demonstrated courage and leadership in their openness and willingness to address challenges (Masotti et al., 2006). FASD can impact not only individual families but also the community itself (British Columbia, 2003). In some cases, interventions may need to incorporate the entire community and thereby help develop community resources that can be utilized by families. The presence of intergenerational patterns (i.e., daily patterns of behaviour and experiences) means that the multigenerational cases of FASD may be interacting with the longstanding history of colonialism. In a qualitative study with eight biological mothers, Johnston and Boyle (2013) noted that the interaction between FASD and colonial history could mean that efforts to address the parenting challenges associated with FASD must also intentionally target the detrimental legacy of colonialism.

Drinking during pregnancy can be conceptualized as a symptom of historical trauma (Badry & Wight Felske, 2013). The origins of trauma within Aboriginal communities began with the colonization of Canada. The colonial period in northern Canada produced severe and ongoing disruption of family systems and Aboriginal culture (Badry et al., 2013). As such, successful interventions from urban areas may require adjustments to reflect the unique circumstances of the rural north. Johnston and Boyle suggest that intergenerational patterns, such as alcohol abuse, have in many ways normalized FASD and weakened the traditional practices and knowledge that facilitate child rearing. However, rural mothers have also demonstrated an impressive resilience and adaptive mothering (i.e., learning from experiences and gaining confidence in their parenting skills; Johnston & Boyle, 2013). Aboriginal parents are faced with confronting the stereotypes that are associated with being an aboriginal parent in addition to the challenges inherent in raising a child with FASD (Johnston & Boyle, 2013). Given that parents are able to improve their parenting skills, based on their own experiences, it seems likely that they would benefit from a collaborative and supportive intervention that addresses the specific challenges of parenting in the north.

There are challenges associated with parenting a child with FASD in a northern or rural context that apply to parents regardless of culture or family history. Challenges include the cost of travelling to access care, wait times, and weather conditions. Boydell et al. (2006) recommend that safe transportation be provided to families who are asked to travel to and from appointments related to care, and that proper childcare be provided when parents are receiving education or support. Using creative solutions, such as online systems, to facilitate the delivery of interventions for parents in rural areas could be beneficial. Although the use of online systems has shown some promise in counselling (e.g., Murphy & Mitchell, 1998) and specifically in a northern context (Garcia-Lizana & Muñoz-Mayorga, 2010; Gibson, et al., 2011; Gibson, O'Donnell, Coulson, & Kakepetum- Schultz, 2011; Jennett et al., 2003; Jong, 2004), the use of online components must be done in an ethical fashion. The need to ensure that online systems do not hinder the benefits of face to face interactions is a pressing concern (Alleman, 2002; Madigan, 2011). Nevertheless, it appears that online components may be of benefit for rural and isolated areas.

Existing Parenting Programs

There are existing models for delivering parental training over distances. A good example of this is the Triple P, or positive parenting program, based out of Australia (Triple P, 2013). This positive parenting program is intended to both prevent and treat behavioural and emotional disturbances in children from the time they are born until age 16. The program offers a tiered system of programs that range in intensity from general information and awareness to intensive programs for specific families that have been identified as facing severe challenges. The tiered system helps ensure that parents receive a level of service that meets their needs without devoting more resources to the intervention than is required. The program is also diversified in its ability to target specific groups (e.g., children with a disability or children who are overweight). Generally speaking, the program utilizes social learning theory, cognitive behavioural therapy, and developmental theory. The overarching aim of the program is to help families become self-sufficient and able to navigate the challenges of parenting without ongoing support as soon as possible. The diverse forms of the program mean that it can also be easily adapted to meet the contexts of specific communities, families or organizations (Triple P, 2013).

A Canadian based program for supporting families, known as the Strongest Families Institute, is based out of Dalhousie University (Strongest Families, 2012). The goal of this organization is to provide cost effective and timely treatment to children who are suffering from a mental health disorder (e.g., anxiety disorder, ADHD, etc.). The programs offered by the institute include chasing away worry for anxiety disorders, dry nights ahead for bed wetting, and chasing away pain for recurrent headaches. These programs use a variety of tools such as relaxation audio clips and access to a coach over the telephone. This program is unique in that its services are designed to be offered at a distance, removing or reducing the need for face to face treatment (Strongest Families, 2012). The Strongest Families team is also developing an online program for parents raising children with FASD. The program is currently in the pilot testing and evaluation stage (NeuroDevNet, 2015).

Need for Additional Research

Given the diverse challenges associated with parenting children with FASD, additional research is necessary (e.g., Clark, 2003; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Davis, 1996; Ragsdale, 2006; Rutman, LaBerg, & Wheway, 2002 & 2004; Streissguth, 1997). Fortunately, current research is starting to demonstrate a new perspective with respect to parenting children with FASD. There is an increased understanding that caregivers require assistance in the form of both formal and informal supports as they confront the complex challenges of raising a child with FASD in contemporary society (Shepard & O'Neill, 2012). In addition, there is a need to look at contextual issues such as parenting a child with suspected FASD in the north (Johnston & Boyle, 2013). However, there appears to be no research that focuses on the experience of parenting a child with suspected, but not yet diagnosed, FASD. Consequently, the current literature can be expanded by exploring how parents experience the daily challenges of parenting a child with suspected FASD and examining how a psycho-educational group can be implemented to support parents.

Chapter Two has provided a detailed overview of the current literature pertaining to FASD research. Chapter Three will provide a detailed description of the research methods used in the current study.

Chapter Three

Methodology

The methodology was initially intended to involve a mixed methods design, and include both qualitative and quantitative data collection and analysis. Foremost, a qualitative research design was used to help address the first research question, "What types of challenges do parents of children with suspected but not yet diagnosed FASD face on a daily basis and how do parents experience those challenges?" This aspect of the research was exploratory in nature and was intended to understand, rather than predict, parents' experiences; therefore, a qualitative design was most appropriate. Both qualitative and quantitative data collection were used to address the second research question, "In what ways can a support/psycho-educational group facilitate the parenting of children suspected to have FASD?" In an effort to evaluate the psycho-educational group, qualitative data collection was employed to gather parents' subjective experiences of the group; the purpose of the quantitative measures was to provide an objective assessment of parenting skills both before the onset of the group and after its completion. Therefore, it was intended that both qualitative and quantitative data collection would assist in evaluating the psycho-educational group; however, as will be explained under the data collection section, there was not enough quantitative data for analysis.

For the qualitative research design, the study utilized thematic analysis and incorporated aspects of the constant comparative method used in grounded theory (Glaser & Strauss, 1967). This was not a grounded theory study, as a theory was not generated.

Thematic analysis is a means of identifying and reporting patterns in qualitative data. Braun and Clarke (2006) note that thematic analysis is flexible in nature, meaning that it exists independent of a theoretical lens and can be utilized across several theoretical and epistemological perspectives. Importantly, thematic analysis, while not limited to any one paradigm, is congruent with a constructivist approach. The data was analyzed using an inductive approach where the themes came from the data; no attempt was made to fit the data into pre-existing coding structure. However, even when the themes come from the data, findings are always influenced, to some degree, by the researcher's theoretical lens. Thematic analysis provided a framework for understanding and honouring participants' experiences particularly as it was not confined to preconceptions and expectations.

Elements of the constant comparative method (Glaser & Strauss, 1967) were used as a way to conduct and enrich the thematic analysis. The constant comparative method involved continuously comparing data units to each other, data units to categories and themes, and categories and themes to each other as a way to determine when categories and themes needed to be integrated or new ones created. A more extensive description of the data analysis procedure is described under the Data Analysis section.

Participants

Participants, recruited through purposeful sampling, were parents of children with suspected but not yet diagnosed FASD (i.e., parents of children referred to a northern assessment team and on the waitlist for assessment and diagnosis). In this case a parent was considered to be the primary caregiver of the child irrespective of whether they were the biological, step, adoptive, or foster parent. There were seven parents in the study. Parents participated in a psycho-educational group as part of a larger project focused on the development and evaluation of the group. The larger project will run the group repeatedly, and the participants for this thesis came from the first offering of the group. Parents and caregivers of children referred by the assessment team to the psycho-educational group completed a pre-screening interview, as part of the larger group project, to ensure that they were eligible to participate in the psycho-educational group.

Participants' ages ranged from 25 to 50 years old. The children being parented by the participants ranged from 5 to 10 years old. Three of the participants were biologically related to the child in their care; four participants were foster parents. Six female and one male parent participated in the study. In addition, all but one of the participants indicated that Caucasian was their ethnic origin. In terms of participants' level of education, one person had an undergraduate degree, two people had a college diploma, two people had completed some college or university, one person completed high school, and one person had some grade school. With regard to marital status one participant was divorced, three participants were married or living as married, and three participants had never been married. Finally, four participants were employed full time, two participants had decided to be stay-at-home parents, and one participant was unemployed due to a disability.

Psycho-educational group inclusion criteria. Participants had to meet a set of inclusion criteria in order to participate in the psycho-educational group and by extension the research: (a) Participants had to be able to commit to attending all group meetings; (b) understand the importance of maintaining group confidentiality; (c) demonstrate that they could function well within a group context; (d) be willing to implement new parenting techniques; (e) have full guardianship of their child or the agreement of all of the child's guardians; other familial guardians were also invited to participate in the group and MCFD guardians were approached if needed; (f) not be participating in another parenting group or program (except as agreed on with the parent and the group psychologist at the time of participation in the psycho-educational group; (g) be over the age of 19; and (h) be proficient in spoken English.

Psycho-educational group exclusion criteria. Participants were unable to participate in the group if, at the intake interview, the group psychologist formed the clinical impression that they were not a good fit for the groups (e.g., evidence of depression or severe mental handicap in parent) or were not ready for group (e.g., because of other commitments that prevent participation in groups). However, this determination was based on professional clinical judgement and did not use any formal assessments. This approach was required since the group is designed to be implemented in northern rural areas where psychologists required to do formal assessments (e.g., clinical psychologists) will not be available. Families who were not suited or who were not ready to participate in the psycho-educational groups were referred back to the intake workers who helped them find appropriate services.

Research study inclusion criteria. In addition to meeting the criteria to participate in the psycho-educational group, participants needed to meet the following criteria in order to participate in the research study: (a) parents had to be willing to complete the required interviews; (b) parents had to indicate whether or not they were willing to complete a journal; parents could choose not to complete the journals and still take part in the rest of the study; and (c) parents had to indicate that they were willing to maintain confidentiality as it pertained to the data generated by the study. No participants who had been accepted into the psycho-educational group were excluded from the research study.

Recruitment

Intake staff from a northern assessment team referred families to the psycho-educational group. The group psychologist's assistant received the referrals and described the group to families. If families were interested in participating in the groups, they were seen by the psychologist and the leader of the children's group for an intake interview. After the intake interview the psychologist's assistant informed parents about this research opportunity. If parents were interested, the assistant asked parents' permission to share their name and contact information with me so that I could further explain this research and invite parents to participate.

Data Collection

An attempt to collect quantitative data was done using the Parenting Sense of Competence Scale. The scale was intended to assess how parents perceive their parenting skills. The intent was to administer the scale before the psycho-educational group and again after the completion of the psycho-educational group. However, the scale was only administered at the start of the psycho-educational group given that participants found the measure hard to understand and some items were worded poorly. In addition, parents did not find some of the questions relevant to their experiences of parenting or their relationship with their child.

The Parenting Sense of Competence Scale asked parents to rank statements on a scale of 1 to 6 with 1 being strongly agree and 6 being strongly disagree. Example statements included "the problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired," "I do not know why it is, but sometimes when I am supposed to be in control, I feel more like the one being manipulated," and "being a parent is manageable, and many problems are easily solved."

The qualitative data was collected through the use of interviews and participant journals. All of the data was collected within six months.

Interviews. The interviews were intended to explore parents' experiences with parenting a child with suspected FASD. They were each conducted using a semi-structured interview guide (Appendix B and C). The interviews were audio recorded with the use of an additional back-up recorder to guard against data being lost due to a problem with the technology. All audio recordings were done using a digital recorder. Each interview took approximately one to two hours to complete.

The first round of semi-structured interviews (Appendix B) was conducted before the start of the psycho-educational group. The interview occurred at a safe, private location that was easy to access for both the participants and myself. Interviews were conducted at the Community Care Center or a research lab at UNBC (University of Northern British Columbia). I described the purpose of the study again and participants signed the consent form (Appendix D) and completed a demographics sheet (Appendix E). I walked participants through the use of the online journal system if applicable. At the end of the first interview, participants were provided with a $20 honorarium in the form of a grocery store gift card. All seven participants participated in the first interview.

The second round of interviews served two purposes. First, member checking was used to examine the credibility of the preliminary data analysis. Parents reviewed a summary analysis of their first interview and reflected on its accuracy. Second, these interviews provided an opportunity to elucidate the issues and themes raised through the journaling process and the first interview. The second round of interviews occurred after the psycho-educational group had been completed. These interviews were completed at the same locations as the first round of interviews. However, if participants requested that the follow up interviews be completed at another location agreed upon by both the participant and myself, this request was accommodated. One participant decided to complete the second interview by phone because family commitments made an in person interview problematic. At the end of the second interview, participants were provided with another $20 honorarium in the form of a grocery store gift card. Three participants completed the second interview. One participant stated that they did not want to do the second interview. This parent was facing numerous work and family commitments and was unable to attend a second interview. Another participant moved out of town during the study and did not supply new contact information. Two participants did not return my calls regarding a second interview. Each participant was called up to three times.

After each of the first and second interviews there was a 5 to 15 minute debriefing session, when the recorder was turned off, so that participants could address any emotions or issues that might have arisen during the course of the interview. The contact information for the intake workers, who helped parents access support services, was available for those participants who requested the information.

Weekly journals. The journals served two purposes. First, they facilitated participants' ability to reflect on their experiences of parenting a child with suspected FASD at an in-depth level (e.g., the meaning they attributed to daily experiences). Second, participants were able to reflect on their experiences as they happened, which hopefully increased the richness of their data. Participants had three options for how to complete journals (Appendix F): using a written online format, using a verbal audio recording uploaded through the internet, or by writing a paper copy. The online data collection system, fluid survey allowed participants to sign in from any location with internet access and to respond to a series of questions each week. Participants were asked to complete the journals at least once a week. However, participants also had the option of using the online journal to record experiences throughout the week as often as they wished. The ability to use the journal repeatedly throughout the week was intended to encourage participants to record and reflect on the daily challenges of parenting a child with suspected FASD soon after they occurred. To make the journal easier to complete participants could simply record their verbal responses to each question and then upload their responses into the survey program. However, no participants chose to complete the journals using spoken responses. Two participants chose to type their responses into the online journal; two participants chose to complete the journal using a paper copy. Participants who completed the journal at least once received an additional $10 grocery store gift card. Four participants completed journals; a total of 10 journals were available for data analysis.

Data Analysis

The data was analyzed through thematic analysis and incorporated aspects of the constant comparative method (Glasser & Strauss, 1967). All interviews and journal entries were transcribed verbatim to facilitate analysis. All transcriptionists signed a transcriber oath (Appendix G).

My approach to the analysis was similar to that proposed by Braun and Clarke (2006) who suggest that phases to thematic analysis include familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (p. 87).

First I read through each transcript in its entirety to get a holistic sense of the participant's experience. Then I used aspects of the constant comparative method (Glaser & Strauss, 1967) to generate initial codes for the data, and documented similarities and differences in the data units (i.e., sentences). Only relevant sentences (i.e., sentences pertaining to the research questions) were coded. I consulted with my supervisor to ensure agreement with respect to irrelevant sentences. If there was disagreement with respect to some sentences they were discussed until a consensus was reached. Then I formed and named preliminary categories by grouping together data units with similar properties. Data units were then compared against these preliminary categories. I did not create categories prior to the study; categories emerged based on the data that was collected. Throughout the process categories were compared with each other and relationships established between the categories. Based on these comparisons and relationships categories were re-examined and integrated or created to reflect the themes in the data. Importantly, memo writing was also used to document observations, ideas and questions related to the analysis of the data. I kept a journal to record my experiences of the interviews and data analysis process. I also used my journal to document my biases and pre-conceptions (e.g., approaching the data from a strengths based lens). Based on the data analysis (e.g., categories) and the information generated by the data analysis process (e.g., my journal) a preliminary interpretation was developed to explain the data.

The preliminary findings for each participant's data were then presented to each corresponding participant during the follow up interview. Importantly, interviews and participants' journals were initially coded individually, to facilitate participant feedback. Participants were asked to determine if the findings, based on their individual interviews, accurately reflected their experiences of parenting a child with suspected FASD. All three participants who attended the second interview confirmed that the individualized findings captured their experiences. I then asked these three participants further questions to clarify or expand upon the existing data. The additional information was used to refine the data analysis.

All interviews and participants' journals were then coded together to provide a composite analysis of the data (Appendix H). During this phase the potential categories were again re-examined to determine which categories could be integrated. It was at this time that I also identified meta themes that cut across categories and participants. The composite included categories, subcategories, and meta themes. This holistic interpretation, drawing on all participants' data, was then e-mailed to participants so that they could evaluate its accuracy. Although participants were not expected to find that every aspect of the holistic interpretation of the data reflected their personal experiences, they should have been able to see their daily experiences reflected in some aspect(s) of the analysis. Participants' feedback was then used to complete a final analysis of the data. Two participants provided feedback attesting to the accuracy and comprehensiveness of the composite findings.

NVIVO

The analysis was done with the assistance of the program, NVIVO. NVIVO was used because the program's coding features helped compensate for my physical disability. For example, the ability to navigate the data using highlighting and colour coding greatly reduced the eye strain associated with theming the interviews.

All transcribed interviews and participant journal entries were imported into NVIVO as documents using the external data function. Once all the data had been imported sentences were coded using nodes to create the relevant categories and themes. A hierarchy of nodes was used to identify how the categories and themes related to each other. The text was selected and coded, to new or existing nodes, as the document was read by simply selecting the relevant sections of text. Importantly, the categories and themes could be moved around within the hierarchy as they evolved throughout the coding process. Journal memos related to specific nodes and/or sections of text were linked to the coded documents to facilitate analysis. In addition, NVIVO could be instructed to analyze all of the transcripts or only specific transcripts facilitating the individual interpretation of participants' data in preparation for the second interview and the final composite analysis. NVIVO allowed for several methods for tracking the categories and themes identified (e.g., assigning a color to each category and theme and using coloured highlighting to denote the different categories and themes). Once all the nodes had been created the program created a code book that captured the hierarchy of the nodes as well as a comprehensive definition of each node. After the data had been coded NVIVO was used to explore the data through a series of searches or queries. These searches could be refined to look for specific comments, search within specific categories and themes and within specific transcripts, and identify relationships between categories and themes.

Evaluation Criteria

The quantitative portion of the study was expected to have methodological rigour. With respect to the Parenting Sense of Competence Scale, Ohan, Leung and Johnston (2000) have provided support for the scale's validity. The scale was found to have good internal consistency (i.e., degree of correlation between items on the scale that measure the same construct) and inter-rater reliability (i.e., the extent to which two parents using the same measure to assess a situation agree). Furthermore, construct validity (i.e., the extent to which a measure actually assesses the phenomenon it is intended to measure) was demonstrated through evidence of convergent validity (i.e., the extent to which two theoretically related measures of a construct demonstrate the presence of a positive correlation) and divergent validity (i.e., the extent to which two theoretically related measures of a construct demonstrate the presence of a negative correlation). For example, convergent validity was seen in the finding that having a low conflict parenting style was associated with higher parenting satisfaction and divergent validity was seen in the fact that having a child who displayed behaviour problems was associated with lower levels of parenting satisfaction. In the present study participants found the scale difficult to understand. The scale was administered before the commencement of the group but not after the completion of the group. The quantitative data provided by the scale was not viable due to poorly worded items and parents' difficulties interpreting the meaning of the questions.

The qualitative portion of the study had several components that helped ensure methodological rigour and provided a clear framework for evaluating the study and establishing the trustworthiness of the findings. The credibility of a study pertains to how well the findings describe the phenomenon being investigated (Lincoln & Guba, 1985). Credibility was facilitated through the use of several methods. All sources of data were audio recorded and then transcribed verbatim to ensure that the data being analyzed was accurate, complete and reflected participants' personal experiences. Sections of the audio tapes were also reviewed by my supervisor to ensure the fidelity of the interview method. Each category contained data from several participants, helping to ensure that the analysis and the findings it supported were not overly influenced by the experiences of any one participant. In addition, the data analysis and subsequent findings were informed by both participants' experiences and my knowledge of the existing literature. The integration of these related but distinct sources of knowledge allowed for the use of triangulation, strengthening the findings of the study. The preliminary categories and interpretations derived from the data analysis were presented to participants, as outlined previously, so that they could be evaluated and refined as needed to help ensure that the findings accurately articulated the experience of parenting a child with suspected FASD. Given that only three follow up interviews could be conducted the findings were also reviewed by two clinicians familiar with the experiences of parenting children with suspected FASD. Both clinicians agreed that my analysis was consistent with their experiences of working with families whose child had FASD. Moreover, sections of the coded data were reviewed by my supervisor to help ensure the consistency and accuracy of the themes that were being used to conduct the data analysis.

Methodological rigour was also addressed through the consideration of dependability, which pertains to the extent that outside researchers can examine the research process and comprehend the decisions that were made throughout the study (Lincoln & Guba, 1985). In order to establish dependability a journal was used to record preliminary ideas and interpretations, permitting a comprehensive review of the analysis process and findings. Another aspect of methodological rigour is confirmability, which pertains to how well the data and the findings are grounded in the events being studied and not influenced by the researcher's personal perspectives or biases (Lincoln & Guba, 1985). Again, the journal kept throughout the study facilitated confirmability by articulating and tracking my personal perspectives and biases. Furthermore, any findings that were consistent with my personal perspectives were rechecked by my supervisor to confirm that they were supported by quotes in the transcripts of several participants. I also conferred with my supervisor to ensure that there was agreement with respect to what constitutes relevant and irrelevant units of data. Confirmability was also facilitated through the use of follow up interviews and having participants check the accuracy of themes and preliminary interpretations. Finally, efforts were made to support the transferability of the research findings. Transferability pertains to how well the findings from a study can be applied to situations outside of the study's original context. Transferability cannot be established by the researcher conducting the original study. Transferability is assessed by the person who wishes to transfer the findings to a new context since this individual has the knowledge to assess how well the two contexts resemble each other (Lincoln & Guba, 1985). An in-depth description of the data is provided so that readers can accurately assess how well the study's findings can be applied to a particular context with which the reader is familiar.

Ethical Considerations

The proposed study was reviewed by the research ethics boards of both UNBC and the Northern Health Authority to ensure that it complied with the ethical standards and protocols of both institutions. There were several key ethical considerations inherent in this study. Parents had to be allowed to take part in the psycho-educational group without consenting to take part in the study itself. This distinction was essential since the need for a psycho-educational group had been identified by parents themselves as a critical resource. In addition, the workers who informed parents of the group could have a pre-existing relationship with some or all parents. As such, there was a need to ensure that parents did not feel pressured or obligated to participate because of who was making them aware of the study. This ethical consideration was addressed by having intake staff members, who did not have pre-existing relationships with potential participants, inform them of the group. Quotes from participants were used in the thesis. To help conceal the identities of participants providing the quotes, the researcher's supervisor reviewed all quotes to ensure that they did not include information that readily identified participants. Participants were provided with contact information for the intake workers and community counselling services at the start of the study, and at the end of the study, so that they could access appropriate support services as needed.

Chapter Three has provided a detailed account of the methodology used in the thesis. Chapter Four will provide a detailed description of the study's findings in relation to the research questions.

Chapter 4

Findings

The findings are based on participants completing semi-structured interviews and journals. Seven parents participated in the first interview; three participants completed follow up interviews. Four participants completed a total of ten journal entries. Two participants also verified that their experiences of parenting were reflected in the final composite findings. Two clinicians, with extensive experience working with families who have children with FASD, verified that the findings were consistent with their professional knowledge.

Daily Challenges of Parenting and Parents' Experiences of Those Challenges

The first research question was, "What types of challenges do parents of children with suspected but not yet diagnosed FASD face on a daily basis and how do parents experience those challenges?" Five large categories emerged from the data; these categories were (a) challenging environments, (b) child's impaired cognitive functioning, (c) child's other medical conditions, (d) seeking to facilitate the child's independence, and (e) child's confrontational attitude. An explanation of each category and a list of associated subcategories is provided. Then each subcategory is explored in detail and participant quotes are provided. Meta themes, which were themes that cut across categories and participants, are presented.

Challenging environments. All parents talked about having to deal with at least one type of challenging environment. The type of environment varied. However, all the environments involved parents interacting with other people or organizations, such as the health authority, in an effort to parent their child, as effectively as possible. The challenging factors related to the environments were (a) insufficient supports for the child, (b) parents not feeling heard by professionals, (c) multiple adults raising the child, (d) regulating video games, (e) social isolation and consequences of bullying, and (f) setbacks related to social interactions.

Insufficient supports for the child. Parents explained that they were faced with insufficient supports (e.g., information from professionals). Parents expressed anger, frustration, anxiety, fear, and fatigue as they sought to find adequate supports. There was a sense of regret and sadness over the challenges their child could have avoided if supports had been available. For example, parents talked about how their child could have avoided struggles in school if proper educational supports (e.g., adapted assignments) had been present. Not having the same support network as other families, without disabled children, who can turn to extended family and friends for help brought up feelings of sadness and a sense of loss. Parents focused on continuously advocating for what their child needed, identifying what kind of services the child needed, providing informal supports in the home, (e.g., working on math with the child) and doing research to come up with new ideas about how to help the child. In addition, parents sought out support from friends and family to help cope with the stress of insufficient supports.

Parents explained the need to accept that receiving professional support, such as a diagnostic assessment, would not solve all the problems. It was important to always seek to reduce both uncertainty and unanswered questions. However, other parents explained it was important not to expect a single universal solution. Some parents mentioned that they were considering moving to a new location that would have more supports. It was also important to find time in the day to talk with the child to see how the day was going as a way to help compensate for missing supports. These talks allowed parents to identify challenges their child was facing and offer support and encouragement that would not otherwise be provided. As parents made progress towards getting more support for their child they expressed feelings of accomplishment, validation and pride. Parents talked about being frustrated by the lack of supports and resources available to their child before they received a formal FASD assessment. For example, one participant explained,

> It feels like that will just be everything, and, I get that's not, it's not realistic, it's very hopeful, to be like hopefully we're just missing this one and everything else is going to fall into place, I understand that that's probably not going to be the reality… I think if he'd had gotten in younger, when we were dealing with more of the behaviours and more of the, but now he's growing, so some of the behaviours are not as severe which is a positive thing, however, I feel like some of his stuff is just because he's just so worn down, he's really accepted that he's just the dumb kid, and I think if we 'd had him assessed earlier they could have got that and we could have put in more supports and hopefully avoided this stage… we just do, try and do what we can at home, try and take him to the library, try and cut out electronics, teach time, when like oh really seizing those, literally we might only have ten minutes, but like ok [he's] in a good mood, I'm going to sit down with the plate clocks and we're going to practice, cause he's actually going to take something in, it's just doing what we can, putting in those supports at home where I can, in a safe environment…(participant 07)

Parents not feeling heard by professionals. Parents didn't always feel heard and understood by professionals. Some parents felt angry and judged; other parents talked about having to cope with the fear that professionals would place the child with another caregiver. Parents talked about how these fears sometimes led to expecting the worst. Parents reminded themselves that they were doing a good job of parenting the child. In other cases, parents spoke of being frustrated because professionals didn't understand what it was like to parent a child with suspected FASD. The expectations placed on parents by professionals were, in parents' opinion, unrealistic. Parents talked about spending a great deal of time trying to get professionals to understand what their child needed and reassuring the child that eventually supports would be in place. Some parents expressed intense frustration and disbelief at the opportunities that had been lost because adequate supports were not initiated by professionals. Despite the ongoing struggle to secure supports parents commented on the steps that had been taken to develop individualized supports for their child and that there had been some successes. One parent said,

> ...I feel like everything that I do is judged on a scale of how well I'm being a parent, and so when I miss something, or I should have done something differently, and I realize that I do a lot of self-blame and a lot of worry, what is the ministry going to think, what are the professionals going to think, are they going to say I should have done it this way, instead of that way... I think that the problem with professionals is that mostly, they specialize in one area, and so if their area is say speech, for example, then in their mind you've got all day to work on speech, but they don't see the whole picture, they don't see all the other things that need to be work on, and all the other all the other things that I see as priorities, because in their mind, they're thinking about what their personal priority is, so and you know, it's like they're thinking why haven't you worked harder on this piece or that piece, when really when you put it all together, you got five kids and they all have different levels of ability and such, there is so much to work on, that sometimes you do never get to their priority...
> (participant 06)

Multiple adults raising the child. None of the biological parents commented on their experiences of interacting with foster parents. Foster parents faced challenges related to their interactions with other people who are helping to raise the child. Foster parents spoke about wanting to have the biological parent involved in the child's life. However, foster parents experienced fear, disbelief and frustration because in their opinion the biological parent frequently could not look after the child without supervision. Some foster parents also talked about feeling betrayed and angry towards the biological parent because the biological parent's actions created problems related to setting up supports and resources for the child. Moreover, foster parents expressed sadness and a sense of loss for the child because the biological parent was not more involved in the child's daily life. Foster parents worked towards trying to have biological parents more involved by anticipating when problems might arise and coming up with creative solutions, such as having the biological parent spend time with the child at the foster parent's home. The child would sometimes become distressed by the absence of the biological parents so foster parents made an effort to be honest with the child when answering questions, helped the child calm down, always focused on being patient with child, reassured the child, and focused on the positive things that were going on in the child's life. Foster parents also decided which things were most important and focused on those first, accepting that other less important tasks might not get addressed immediately. Despite feeling fatigued, foster parents expressed feelings of accomplishment as they found ways to integrate the biological parent into the child's life. These successes gave foster parents a sense of hope that progress was possible. A parent commented,

> …well there is, in that similar to parents who go through divorce we are sharing children with other parents, so they have their birth parents, that are also their parents and so we have to be respectful of them and of making time for them…the youngest one, they also spend time with their mother, their natural birth mother, so on a visit to mom's the youngest one left the home… left the home, went out on the street… the police phoned us, we have your child, um, so like that's the kind of thing that can happen if people aren't aware of the dangers…so she has a visit in our home, but not at her home, so we supervise her time with the kids, so she comes here to see them and so that's what, that's sort of our solution around what do we do, when we really feel like it's not safe, is we just say "sure, you can have a visit, but why don't you have it here, why don't you come over and play with the kids at our house"… (participant 06)

Regulating video games. Some parents found themselves having to regulate their child's use of video games. Some parents regretted giving their child access to video games because the child would copy the aggressive and disrespectful behaviour used in the game. Parents resorted to using methods that they identified as not very effective, such as yelling. This type of approach did not work because the child became angry and it became very difficult to communicate with the child. As an alternative parents started anticipating which games the child should not play (e.g., Grand Theft Auto) and being consistent with rules around which other games could be played (e.g., Lego). Parents also took time to explain the rules to the child and helped promote informed choices by making the child aware of what the consequences were for breaking the rules. Parents found some games that fostered cooperation. These skills based games actually helped improve the child's behaviour. One parent stated,

> ...I took his game away for two weeks – no, for one week at first. It was to the point, where every day he was calling me an idiot, ordering my around, this and that. He brings his friends over, he calls me names in front of them. As soon as that happens, I go like this, "Out! You guys need to leave. That goes off." Then it's a big fight. So the last time that happened, I took everything, put it in a box, taped it up, all the games and all the electronics, everything. I just threw it in a big box, taped it up and left it there. It stayed there for a week. He kept apologizing. I said "I'm sorry, I gave you a week, it's staying there ..." It felt good. And he was doing better. But, yeah, I should've done that a long time ago, packed up that machine and the game. I've done it twice now and we had a peaceful week when I did it....I find, when he plays certain games, he tries to act to character, he tries to be mean...I bought him all the Lego ones, I try to get him to play the Lego games because I notice when he plays those he's happy, he gets along with everyone. But when he plays those other games, he's controlling and he gets mean and he just starts flying off the handle...(participant 02)

Parents found some games that promote skills, such as math. These skills based games promoted comprehension. Other parents found video games beneficial because they allowed their child to interact with their friends in a collaborative way (e.g., Minecraft). Parents found video games to be at least partially beneficial as long as their use was tailored to meet their child's needs. For example, parents would pick games that targeted academic skills that needed to be improved. Being able to transform a challenge into a potential solution gave parents a sense of validation and pride. According to one parent's experience,

> ...if you are going to play this, you know ninja game for half an hour, you need to play a math game for at least 15 minutes and so trying to get him to go through all those apps and find games that interest him... his friends, a lot of them play Minecraft which I love for him, it was just the perfect combination and for me, as a mom, just a fabulous combo, he loves Lego and always has all those very hands on intricate and it just lets his imagination go, so to see that but then, it also allowed him to interact with all of his friends, they can chat, they can build things together, so that socially it was good for him he has a lot of really great little friends... (participant 07)

Social isolation and consequences of bullying. Parents explained that they worried their child would become socially isolated as peers matured. This concern was particularly important as parents thought about their child eventually going to high school. Parents experienced fear and frustration at the prospect of their child becoming socially isolated. Parents spent time anticipating what might lead to this isolation (e.g., impaired social skills) and sought to prioritise teaching their child skills essential to increased independence and maturity. Furthermore, parents spent time explaining skills and reassuring their child that progress and improvement were possible. As with other skills, parents felt a sense of pride when their child started to acquire a new skill that would reduce the chances of social isolation. One parent explained,

> ...he's 10, and in many ways he's 10 as are his friends, but kinda of social emotional, we're still seeing him more around 7, 8, and so, um, my fear is that some of these friendships are going to, kind of outgrow him and that concerns me because, he just he is so social and he is so sensitive and the friends he has, he, they are like his buddies, for life, but I can kind of already, start to see the way some of them are just, they're maturing... (participant 07)

Some parents talked about how their child was already experiencing social isolation and bullying. Parents felt angry and betrayed that other adults had not stepped in to help prevent the social isolation and bullying. Parents spent time letting the child talk about being bullied in a safe environment and helped the child regulate emotions. Parents also advocated for their child and tried to put supports in place that would stop the bullying. Parents explained that they were committed to helping their child through the bullying but always being exposed to the child's anger and frustration was exhausting and overwhelming at times. One parent explained,

> ...he gets picked on at school, all the time. Like I said, with the bathroom thing, he won't even go to the bathroom at school anymore, since those kids did that to him and they are always shoving him in the hall, always pushing him around. I'm

> surprised he stuck it out that long…I have to lay with him, when it's bedtime and rub his back and we talk – that's when we have our talks – I give him his melatonin, and then I talk to him and ask him how school was and he's more relaxed and he'll tell me… (participant 02)

Setbacks related to social interactions. Parents also explained that their child experienced setbacks related to social situations, such as interactions with peers and teachers. Parents felt angry and at times fatigued in response to such setbacks. Some parents made a point of deciding which issues were most important and which ones could be dealt with at a later date. Other parents experienced fear and anxiety over how their child would interact with peers. A major concern was that the child would become a follower and be manipulated by other children.

Parents talked about how they felt betrayed and let down by staff who failed to adapt schoolwork so that the child could learn. The feeling of being let down was increased by the fact that parents took time to explain their child's needs and advocate for accommodations in advance. However, parents felt their concerns and the information they provided were not used by teachers. Parents often broke tasks, such as homework, down into steps to make them more manageable. Parents also found creative ways to mediate the setbacks their child was facing (e.g., getting a private tutor). Moreover, parents focused on making sure that their child would be able to make life choices. Avoiding setbacks in social settings, such as school, was vital because parents did not want to unnecessarily limit their child's opportunities later in life. Eventually, parents want to see their child have the confidence and skills to stand up and advocate for what they want to do with their life.

Parents talked about spending time explaining and teaching the child skills that they had not previously learned. Parents explained that in some cases the child simply had not had the chance to learn a particular skill. Seeing the child learn a new skill or make new supportive friends gave parents a sense of success, pride and progress. These accomplishments made it easier for parents to deal with the ongoing uncertainty of how the child would handle social settings as they matured. One parent described,

> …sometimes she can be very bossy, so it's kind of hard when, but it's like, any kind of child can be bossy per se , but with her, I think with her with the FAS, it's kind of a bit more of a struggle with her, cause she kind of doesn't understand, when you're telling her that you know, you got to step back, we got to take turns, we have to share, um, she's very like loud shall I say, and she can get really silly easily and some of the other kids don't understand… a girl will come up and be like oh hey, you know, talking about something and she'll kind of look at her and go ok, and then go off and start going back to that other friend she had seen and was like focused on, like she's not able to, like if she has one thing on her mind, she can't have another child come up, and I think she brushes them off and I don't think she means to be rude… her teacher had saw her and came up and is like, oh hi, and she's talking to her and everything like that, and she's like, "where's my class?" I'm like "someone's saying hi to you, look", no she couldn't focus, she knew we had to go look for her class and she couldn't, like at least with the teacher, it was kind of like, you know, but if another child does it I can see where they're kind of put off…I'll tell her I talked to her afterwards and said, "you know it was ok, we had time, that you could have said hi to your teacher, we would have found your class after, it was ok…" it was just try to like help her and the next time something like that happens, that you can take a break, to talk quickly and yeah… she helped a friend go down [in the swimming pool] and brought up a ring for her friend… I feel pride, like just you know happy and that you know it's, the good things that's coming out of it… she dives down to get her one and you think oh well you know she could have came up and said "I have two! I have two!" But she handed it over and she had one with the other girl…just like happy and caring and all that kind of stuff, like just like you know, makes you kind of thrilled, like you do feel like high in a way…(participant 03)

Child's impaired cognitive functioning. All parents were helping their child cope with the impact of a cognitive deficit. These challenges ranged from children not being able to understand concepts, such as math, to an inability to know when a situation is unsafe. The subcategories of child's impaired cognitive functioning were (a) child's anger related to having a cognitive deficit, (b) child not understanding information, (c) child finding change difficult, and (d) child not understanding when a situation is unsafe.

Child's anger related to having a cognitive deficit. Parents talked about how their child knew about the cognitive difficulty created by suspected FASD. The child was often angered by the challenges and limitations that existed. Parents explained the need to determine which issues could be addressed and which issues were beyond their control. For example, parents could help their child cope with the inability to fully comprehend the absence of a biological parent but could not always reunite the child with the biological parent as often as the child wanted. Parents also described feeling depressed and anxious as they watched their child come to terms with having cognitive impairments.

Parents were angry and frustrated that they could not always help their child overcome cognitive challenges, such as understanding math. Parents used several skills to help temper their child's anger, such as being honest when they didn't have the information the child wanted, consistently helping the child try and find ways around challenges, and explaining things in a different way when the child didn't understand and became angry. In terms of being honest with the child and trying to find a solution one parent commented "…You need to sleep. I can't tell you that answer because I don't know it. I'm waiting to hear back…we can call once it's the morning time…" Parents commented on the importance of helping the child understand the consequences of their actions since the child often became angry when the reasons for consequences were unclear. However, it was important for parents to find moments when the child was starting to calm down. Proper timing of information helped reduce the child's anger. Waiting for the right moment also meant that parents needed to be patient and often let the child vent their anger before a conversation could happen. Some parents expressed fear over how they would manage when the child was a teenager and became angry. The concern was that eventually the child would be stronger than the parent and someone could be hurt when the child was angry. Other parents commented that it was important to model for the child, through pictures and demonstrations, how a person who is angry should act. Some parents would actively remove something from the environment that was making the child angry, such as homework. The child was reassured that once the anger had passed the removed item would be returned. Parents actively sought resources and supports, such as educational groups, that could help manage and reduce their child's anger. Parents believed that being consistent with rules and expectations helped reduce their child's anger. These accomplishments gave parents a sense of relief and accomplishment. However, some parents expressed feelings of dread and fatigue as they faced the challenge of managing their child's anger later in life. Specifically, parents worried about their child's anger in relation to high school and the increasing academic demands. One parent summed up an experience,

> …when he gets angry, he brings that up. "Well, it's because my Mom and my Dad did drugs." I said, "Well, yeah but you don't have to act like this. There is a way around it. You just have to stop, you have to think before you talk, you have to try"… if he's mad I'll get him to talk about something else. We come back to it when you're calm… I just tell him the truth. I try to rephrase it so it's not, so it don't sound too harsh on him. He's gotta realize he can't do things like this… if he flipped out, so he wouldn't hurt anyone else or me or whatever. I'd sit on the floor with him, put my legs and arms around him and I'd hold him until he calmed down. But he's nine years old and he's getting stronger and he's getting too old for that… (participant 02)

Child not understanding information. A cognitive impairment all parents faced was their child not understanding information, such as spoken instructions or written information. Some parents talked about feeling anxious and angry when their child could not understand something because the lack of comprehension made it hard to help the child. Other parents had a sense of fascination and disbelief related to the fact that the child understood some information well but completely missed other instructions. Parents had a strong desire to figure out how their child interpreted and remembered information. Parents focused on making sure their child understood information so that eventually the child would be able to make their own choices and decide what to do with their life. To help facilitate this freedom of choice some parents focused on deciding which skills the child will need to know in the future, such as how to count money, and which skills are less important for the child's future, such as knowing how to use the Pythagorean Theorem. Many parents broke tasks down into steps, explained things repeatedly in different ways, and made sure the child had time to talk with the parent each day. Foster parents described that sometimes the child did not understand how to do a task simply because it had never been properly described or demonstrated before. Other parents found that they had to give information in small chunks and then give the child time to process what had been said before providing the next piece of information. Other useful skills included having the child repeat verbal information, writing instructions down in a list, using simple words when talking to the child, and changing the expectations placed on the child when needed.

Parents commented that it was important to check the child's comprehension because sometimes the child would give the impression that the information had been understood when in fact the child was just trying to end the conversation. The fact that every child understood information differently left parents feeling exhausted at times. The task of finding the unique solution for each child could be daunting and different strategies were often needed for different kinds of information, such as spoken or written instructions. Other parents spoke about how they wanted to change the strategies that had been used in the past because these approaches had not worked well. Parents talked about how they were able to increase their child's understanding somewhat, even without enough formal supports, and this gave parents a sense of relief and success. However, some parents remained protective of the child and often worried about a negative outcome if the child's comprehension would not improve considerably. For example, some parents talked about the possibility that the child could be placed with another caregiver. The fear was that the professionals would recommend another caregiver, presumably with more resources and energy, as a way to facilitate the child's cognitive development. According to one parent,

> ...talk about why some things are not a good choice and what better choices could be made...trying to get him to think about choices he's making...when something happens, then I try to think about, okay, um, on a scale of one to ten, how important is this with everything going on for him, um, like life factors all considered, what's important? What, what does he need to know how to do? What's a life skill?... Lots of times what I'll do, um, with kids, to make sure that they've heard me and understood me, is I'll tell them something important and then they'll say, "Okay." And I'll say, "What did I just say?" And then that way when they repeat it back to me, then I, I have a better understanding. How much they understood of it...It's like, how come you know what it was yesterday when you cannot do it today?... and yet you know the theory? You know it all to be true...and here it is happening right in front of you and you're still like, This is amazing! (participant 01)

Child finding change difficult. Other parents explained that their child found changes to routine hard to accept. Parents felt anxious and fearful when their child needed to adjust to a change. The need to constantly anticipate and mediate changes was frustrating at times for parents. For some parents this frustration turned into feeling fatigued and anxious. Some parents used skills such as being honest with the child about the drawbacks to change, making the child aware of how change can be positive, introducing changes in gradual steps, allowing the child to make some choices around how change was handled, and being mindful of when the child was finding the change especially hard. Parents emphasized that there was a need to be patient with the child and allow them to accept the change gradually. Other parents used skills such as encouraging their child to keep trying new things as a way to make change easier. When the child felt uneasy about change, parents helped by offering frequent reassurance and encouragement. Parents were comforted by the realization that with persistence the child usually embraced the change. Parents expressed a sense of relief and accomplishment once the child was familiar and comfortable with the change. One parent commented,

> …it's definitely worse through transition periods, for example, we just moved to a new house so that took months of prep work, just introducing the idea, um, those big transitions are hard, he's definitely grown a lot over the little transitions… Sometimes, it definitely brings some, anxiety, so mentally, I have to prepare myself and often, you know and I like ok, you know tomorrow this is going to happen for him so, (sigh) so let's get on the same page here, take a breath and be prepared to get him through that… I was able to be really sensitive, I think I feel like I was, when we said ok, you know we sat him down, said, um, when we had narrowed it down to two houses… we had to be really careful, I didn't let him, I did all my online stuff and all my looking at homes in the day when we first started, because I didn't want it to come off that change was coming and I didn't, because he doesn't sleep, which carries over into everything else… Yeah, and the one house we ended up buying… he loved you know, and I really made him and my step daughter, we went and picked out paint colours for the room and new bed sets, really tried to make it a positive thing and they got to be a big part of it and they both transitioned very well… you just have to be really prepared that you're going to be dealing with it and it's typically, like one or two main concerns he has just repeatedly come up, you have to make sure you know, you're kind of always giving the same answer because he just really needs the reassurance, like this one, um, with the move he's really afraid he's going to lose friends, you know, and sometimes, I say "and you're allowed to be sad, absolutely" you know, I give him that, "you know bud, I've had to move and I get it, it's sad to lose friends…" (participant 07)

Child not understanding when a situation is unsafe. Some parents experienced intense fear around their child's inability to determine when a situation was unsafe. Parents focused on anticipating risks, such as harmful objects, so that these items could be removed from the environment. Parents also had honest discussions with the child about the need to be cautious around people they don't know and the importance of following rules, such as not leaving the yard alone. Parents also used concrete demonstrations that included drawing a line on the ground to show the child the boundaries of their play area. In addition, parents sought support from trusted people to help supervise the children.

Parents were often hyper vigilant and expressed confusion over their child's inability to tell when a situation was unsafe. Parents coped by reminding themselves that there was only so much anyone could do to protect their child and some degree of uncertainty and risk was unavoidable. After taking every reasonable precaution some parents found comfort in their religious beliefs and felt that God would help keep their child safe. Moreover, parents struggled with finding a balance between permitting more independence when the child was ready and still keeping the child safe. Parents explained that the constant challenge of keeping the child safe was complicated by the uncertainty of how this challenge would change as the child matured. A parent described,

> ...another big one, that keeps me up at night and that's more concerning the girls and safety. Also [my son] and safety in different ways. So none of them are safe to let we have a locked gated porch for a reason, even though their ages would suggest that they could go ride their bike on the street or they could walk across the street to the neighbours, they cannot do those things safely, I have not been able to teach them to look both ways, I have not been able teach them not to approach strangers, I haven't been able to teach them what is potentially dangerous. .. we just keep our place really ridiculously safe... we baby proof for 8 year olds basically, everything that's potentially dangerous is locked up, everything that's a potential danger... we have part of our house, is locked off to the kids, downstairs where our room is, because that's where we keep anything that we think might be dangerous, and the girls, the older girls room, is also not open for everyone to play in... anything, that we think the little two couldn't handle, has to stay in that room... things like a bouncy ball, we can't have a bouncy ball out of the room because [he] will put it in his mouth...I am Christian and so I think, at a certain point, you just have to have faith that, um, that things are going to work out, at a certain point you have to know that there is some protecting force that exists beyond us because we can't protect everybody from everything... (participant 06)

Child's other medical conditions. Parents talked about their child likely having other medical conditions in addition to the suspected FASD. Parents felt angry, fearful, and anxious as they dealt with their child's suspected additional medical conditions. Parents spent time meeting with medical professionals in an effort to determine what other conditions their child had. However, as noted previously, parents did not feel that professionals understood their concerns and that there were insufficient supports for their child. Some parents felt depressed and were in disbelief as they tried to help their child cope with undiagnosed conditions. Other parents feared that the undiagnosed medical conditions could cause permanent damage to their child's physical health. In some cases the undiagnosed medical conditions, such as hypersensitivity, were compounded by the suspected FASD. The child did not understand and/or remember to eat regular meals and the hunger aggravated their hypersensitivity. A parent explained "...[he's] like no I'll just eat at the park... [I'm] like no, you need to eat now [son] because by the time we... get to the park... you're not going to be able to manage..." Parents felt overwhelmed, at times, having to deal with multiple concurrent medical conditions. Despite feeling overwhelmed, parents described the need to be patient when interacting with their child. Parents used several strategies, such as doing research to come up with potential solutions, getting support from friends and family members, and setting up a schedule for essential tasks, for example eating. Through trial and error parents found ways to manage some of the other medical conditions which gave them a sense of hope that progress was possible. Parents sometimes felt it was not possible to manage their child's medical conditions; at these times there were feelings of hopelessness, dread, and a need to give up. However, parents' love for their child made it easier for them to persevere. One parent remarked,

> ...he had a seizure when he was in kindergarten... So he's got a combination of [medical conditions] It's just one thing after another...How can a kid sit there with his eyes rolling to the back to head and his head twitching and then his mouth stretching, and it's constantly his head going back and his eyes are going, and he's right in front of the TV... That was starting to bug me, I took him to the hospital for that and that's what they told me. He'll be like this for three or four months and then he won't do it for the longest time and then, out of the blue, one night when he's watching TV he'll start with the eye thing, or the mouth. He'll start with one of them and eventually it'll be two of them, then three, then he's doing it all together, back to back, with seconds apart. Like, that's how bad it gets. So they haven't even checked

> him for that yet…it scares me…just like you never get over seeing your kid take seizure…I'm trying to understand a lot, trying to take in a lot, but, that's what I said, I need to be able to go out into the community and find people that are going to teach me more about this. And I find that if you talk about it with other people that are doing the same, that are going through the same thing, that helps too…. I get depressed… I've been having anxiety attacks where I can't breathe… (participant 02).

Seeking to facilitate the child's independence. All parents identified challenges that needed to be resolved so their child could be independent. Some of these challenges were situational, such as teaching the child how to do laundry. Other challenges related to how the child's emotions impacted the ability to respond to situations. The subcategories of seeking to facilitate the child's independence were (a) facilitating problem solving and taking responsibility, (b) reducing the child's dependence on the parent, and (c) helping the child self-regulate.

Facilitating problem solving and taking responsibility. All parents wanted to help their child solve problems independently and take responsibility for their actions. Parents expressed feeling angry, frustrated and fearful when their child found independent problem solving difficult. These emotions were related to parents' concerns that the child would not be able to live independently and parents worried who would care for the child later in life. Other parents also talked about feeling depressed over the realization that their child may never be able to live independently. Parents focused on deciding which skills, such as doing laundry on their own, were most important for the child to achieve independence. Parents felt fatigued by the task of helping the child to become independent so it was vital to decide which skills needed the most attention.

Sometimes the child would become discouraged when a task seemed too hard. Parents reassured the child and explained that the child only had to be willing to try. One participant stated, "I don't care if you make a mess. You make a mess, you clean it up." If the task was not done successfully there would always be a chance to try again. Importantly, some parents explained that taking responsibility also meant that their child would eventually make their own informed life choices rather than just being able to solve simple problems, such as washing dirty laundry, on their own. Some parents talked about having to simplify their expectations and re-teach foundation skills (e.g., basic math) which the parents thought the child had already learned. Other parents got help from neighbours who agreed to act as an emergency contact so that the child could practice steps towards independence, such as being home alone. Having these supports made it much easier for parents to simulate independence for the child while still maintaining the child's safety. A few parents talked about the need to remove barriers to independence by reminding the child that with each new day past disagreements or failures no longer existed and the child could confront the day with a fresh start. It was important to keep the child focused on successes so that they didn't become discouraged. All parents spoke about steps their child had taken towards independence and these accomplishments validated parents' ongoing efforts and commitment to support their child. One parent recalled,

> ...I signed him up, he did a computer summer camp here, loved it... he left with more skills and then he decided for his birthday, um, school has suggested, maybe he gets an Ipad... for his birthday, we talked to him... if you do jobs around the house, you can save up, we told him if he can save up 200 and we said, so we had a year and then we would pay whatever else... he, you know, he shoveled driveways, he did whatever for grandmas and grandpas and he did a lot of it and so that was good too because it was constant, like ok, let's count your money, lay it out, ok, so how much and you know, here's the lump sum you need minus what [we] are going to pay minus, you know, and so the whole process was great, um, and he got it, and it's been wonderful, it really is and it's been very helpful in a lot of ways, so there is that comfort that he's gonna be ok... at the same time pushing him, I don't want him to skate through doing minimal... he needs to get other skills but we need a starting off point and things like math and telling time and then numbers that are essential for the rest of his life... some things he just has to learn, whether he learns it kicking and screaming, every

> step of the way, it doesn't matter he has to learn it or he's going to crash and burn…I try and tell him, "you know buddy, maybe you're not going to live up north all the time, maybe you're going to move to a bigger city… you're probably not going to have a vehicle there, you're going to have to learn to ride, to use the transit system… you need money to buy those tickets, you need, so there's budgeting…" it's exhausting because there's so many things he, we, should just be past …(participant 07)

Reducing the child's dependence on the parent. Some parents dealt with trying to ensure that their child did not become overly dependent on them for support. Parents worried that because challenges could be discouraging the child would not become as independent as possible. Parents expressed anger over the fact that their child would sometimes assume a task was too difficult without even trying and look to the parent to always explain what needed to be done. Parents talked about needing to remind themselves that they were not always responsible for the child's mistakes and sometimes the child had to experience consequences as a learning tool. Finding time to talk with the child and explain why consequences occurred were very important so that the child would start to understand how actions impact outcomes, such as having to get up early to put clothes in the dryer so there would be dry clothes for school. Some parents tried to reduce their child's dependence on adults by showing the child all the fun opportunities that would come with increased independence. Other times parents changed the environment. For example, parents bought foods that were easier for the child to prepare on their own. Parents with older children were relieved when signs of increased independence appeared. Some parents with very young children felt extremely protective and talked about trying to not create unnecessary dependence. Having a child with suspected FASD was unique because parents found themselves not always insisting that a child learn a skill or complete a task. Parents described that right now it was hard to start building independence because of the child's age and undiagnosed FASD. Parents also realized that there was a need to ensure that expectations were gradually increased over time so that the child would be able to develop independence. A parent commented,

> ...I mean, she can live with me till (laughing), you know, she's 60 but I would like her to be independent...You know, she did cross-country running too... She didn't wanna do it but I talked her into it. So they were doing the cross-country running and the first race we went to, she look fine. She was running and running and when she came to run back, and there was all these people lined up and everybody was yelling and cheering and she'd come around the corner and she saw everybody, and I seen her. She just like boof. She was done. And then she saw me and my husband and she just started crying and she ran for us... the kids were all, Finish the race! Finish the race. I'm like, "No. She doesn't need to finish the race. She's fine..." something that would be interesting to be able to develop as a tool, and to be able to talk to her about what she's feeling at that moment...be able to have- she can verbalize that...maybe I can give her the tools to help her with that...they'll become times in her life where she's gonna need to be in a crowd, right. She's gonna need to do something and [I am] not gonna be there to go, "You know what! She doesn't need to take notes..." (participant 05)

Helping the child self-regulate. Another challenge related to fostering the child's independence was helping the child learn to self-regulate their emotions and behaviour. Parents were particularly concerned and angry about their child's lack of self-regulation because the child had to be calm before other challenges, such as lack of understanding, could be addressed. Parents talked about being fearful when they thought about their child getting into trouble with peers because of poor self-regulation. In some cases, the reason for the child's poor self-soothing was unknown which left parents feeling frustrated because there was often no way of helping the child calm down. In these instances parents talked about the need to accept the absence of an apparent cause. Parents also had friends and family with whom they could talk as a way to express their frustration at not being able to offer more help to their child. Helpful parenting skills included picking up on cues that the child was escalating and then helping the child calm down, finding times when the child was able to practice self-soothing techniques and, when possible, removing triggers from the environment. Although parents identified ways in which their child's self-regulation had improved there was an ever present concern that the progress was temporary. Some parents were caught between feeling validated by the progress and fearful of progress being lost. A parent explained,

> …I had asked her to clean up her toys and I gave her warnings and everything. She did not like it. And she instead of, um, screaming or anything, she was going to come up and hit me. And I was "like, Oh, remember?" Cause I have a house rule list of what stuff we're allowed to do and what we're not allowed to do in the house… And I said, "Stop, remember." And I just showed her a picture of the wall and she just stopped herself… I was very happy… I mean some days I just want to get in her head. Be like, Okay, why is this going on?... what's happening before we get to the screaming? Cause, like, sometimes, you know, by the time we're done it all, I'll ask her and she won't even understand, like why she was doing it… And just those are, like, the things where I just get, like, lost and confused… very frustrated. I do and there's a bit of a support group for ah, stuff like that like, so I do have a worker I can talk to, myself, so it's kind of like my support, in a way, for that, but so on those kind of issues… I have but, sometimes with those you can kind of talk to them and kind of have a bit of a relief… It's hard… it's just all uncertain… we just jump off, flood the deep end and hope we can swim, that's basically what it is and like, you know, one day we may end up drowning a little bit but, hopefully, we can pull ourselves… I try not to dwell on it, too much I think, because I don't want it to overrule everything else, positive, going on, but it's also, it's hard, because you just don't want to let your guard down and be disappointed, in a way, and it's nothing against her per se, it's just like, ok, what do we know, we have to get back on track… (participant 03)

Child's confrontational attitude. At times parents had to help their child communicate in ways that did not include physical or verbal aggression. However, this challenge made the use of parenting skills harder since the child needed to be calm for many of the skills to be effective. The subcategories of child's confrontational attitude were (a) experiencing child's verbal disrespect, and (b) dealing with child's physical aggression.

Experiencing child's verbal disrespect. Parents sometimes found themselves dealing with a verbally disrespectful child. Some parents had a sense of dread, fatigue, and being overwhelmed when their child was disrespectful. It was very difficult to work on other challenges when the child was being verbally disrespectful. Some parents became angry which intensified the child's behaviour. Parents described that they preferred to use such strategies as removing video games for a set period of time, knowing when to give the child some alone time to calm down, helping the child understand the hurtfulness of their words, and explaining consequences after the child had stopped being disrespectful. Some parents commented that times when the child was disrespectful were useful in that there was an opportunity to have the child practice self-regulation. Other parents talked about wanting to learn new strategies so that there would be no need to use methods that parents found ineffective. The ineffective strategies only made the child more angry and disrespectful. Parents were disappointed that more resources and supports for anger management were not available. One parent said "...at points there he gets so angry I don't know what to do, then I start getting mad..." Parents commented that being consistent with rules and expectations could be exhausting. However, consistency reduced the instances of the child being disrespectful. One participant recalled,

> ...some days, it just kind of spirals everybody, he gets in a mood and he knows, so he'll push and push and push, misery loves company, until I'm yelling or he's being so disrespectful to me, in his tone of voice, and the language and then [my partner's) like, "do not speak to your mother like that, it's rude," and then, they're going at it and finally, it's just ah, and then, it's really hard... I said, "you know what, grab something to eat, disappear, just give me half an hour finish the dishes, get the kids going, I'll take the girls to daycare, and then we'll go from there..." well, but what did I do? I just explained to you, just take a breath, go, go do something... (participant 07)

Dealing with child's physical aggression. Other parents found that their child could be physically aggressive (e.g., hitting). Parents commented that they were anxious and at times fearful. Feelings of anxiety were related to not being able to understand why the child became aggressive. In the absence of a potential cause, parents were often unsure of how to help correct the behaviour. Feelings of fear stemmed from the unpredictable nature of the aggression and parents worried how they would respond when the child was older and stronger. Some parents expressed regret that the only solution they had found so far had been to restrain the child. Parents were eager to learn new, nonphysical ways to reduce the child's use of physical aggression. Parents explained that there was a need to try and anticipate what might trigger an outburst while also accepting that an explanation may not emerge. After the child had calmed down, parents repeatedly spent time explaining why the child's actions were not acceptable and trying to help the child find other ways of coping with being angry or upset. Some parents also noted that they tried to teach the child to engage, without reminders, in using self-control. One parent commented,

> … If you make him escalate, then he's gonna start swinging and he's gonna start throwing things… I wrap my legs around him when he blows up… if I had to sit on the ground in the grocery store, if I had to do that in grocery store or anywhere, I would do it. You know? To stop him from hurting me, himself or anyone else….he calms down after a while. We just need to separate. He goes into his room. He's still angry… I told him, "If you want to get mad, get mad. But, don't take it out on the walls, don't take it out on me. You want to be angry, then be angry…Keeping all that in will make it worse in the end." I don't want him to stop getting angry, he's got to get it out. But there are other ways to take it out… I need to find a better way to be able to deal with him, I don't know what to say to him half the time… (participant 02)

Meta Themes

There were four themes that were present in all parents' interviews and occurred across challenges. These themes were (a) parents' hope, (b) parents' frequent self-reflection, (c) understanding the child's perspective, and (d) parents' flexibility and creativity.

Parents' hope. Regardless of the challenge all parents felt a sense of hope and believed that progress was possible. Past successes and positive experiences gave parents a reservoir of determination. Confronting challenges and setbacks was made easier by parents' sense of hope and determination to work towards solutions. The enduring sense of hope offset feeling of weariness at times. One parent recalled,

> ...I started crying... she did read her first book... and that was like a huge accomplishment for her... it's amazing... and hope you know, that, Okay, maybe, maybe, we can do this, maybe, I don't have to be so afraid of everything that she does... (participant 05)

Parents' frequent self-reflection. Parents spent a considerable amount of time reflecting on situations and challenges. It was useful to reflect on helpful and unhelpful parenting behaviours. Some parents realized that they did not have to assume responsibility for everything their child did which made it easier for them to let go of self-blame and unconstructive criticism. Other parents found self-reflection helpful but spoke of the need to remember that it was impossible to understand the reasons for every aspect of their child's behaviour. Finally, self-reflection and self-awareness allowed parents to know their limits. Knowing when to step back from a situation and take a break made it easier for parents to feel less fatigued and angry. One participant explained,

> ...cause I always, you know, at the end of the day I like to sit and think about how I handled everything and, you know, what things maybe didn't feel the best to me... That I would get caught up in... people saying, "well, he did this at school..." now I just feel like I can't help what he does at school. I'm not there... I don't know what the circumstances were... I can only talk to him about what he does when he's with me... I can talk to him about why it's not a good idea, when it is a good idea, but I don't like feeling the pressure from school or daycare, um, that I can correct something that happens in that environment... sometimes it'll be, "uh, maybe just go play in your room for a little bit 'cause I need to have some thinking time..." (participant 01)

Understanding the child's perspective. In most situations parents made an effort to understand events from their child's perspective. One parent stated "...you gotta look at it through their eyes, listen to their ears, think what they think, hear what they hear, know what they know... but in order to do that you have to get inside... a kid's mind..." Looking at situations from another point of view allowed parents to appreciate how difficult certain things, such as not being able to understand the world, must be for their child. This deeper understanding of their child's world often made it easier for parents to be patient. Furthermore, looking at situations from the child's perspective often facilitated the development of new skills or solutions for challenges. One parent said,

> …I tend to give her a little bit more leniency, I think, too… I think that some of the stuff that she does is probably outside of her control… by yelling, it escalated her too… you have to sort of visualize a kid who... and I use the- I always use the word "shut down"… like you literally just see her go, Diuup! and she's, like, gone…she'll just kinda like, stare off… and then you think, okay well, while she's protecting herself... and that's what it is, right… while I'm yelling at her, she's protecting herself, she's really not absorbing everything else I'm saying… If I could not yell, that would be better… (participant 05)

Parents' flexibility and creativity. Parents constantly demonstrated flexibility and a desire to find creative ways of helping their child. Moreover, this creative tendency seemed to almost always be present. Some parents even generated creative new solutions over the course of our interview. Their creativity and flexibility helped them cope with the fact that each child required a different solution. In addition, solutions that helped the child changed over time and from one situation to the next. All parents sought resources and supports that could help fuel their creativity a parent remarked,

> …we've been just trying different things and I just had a moment of why am I trying to teach him at a grade 4 or a grade 5 level? He's not there, and these are the moments of like, how far back do I go?... ok, we need to bust it down to a kindergarten level to teach [him] because my nephew gets it and he's in kindergarten, so we went home, broke it down there, and [he] got it… teach young children how to tell time just using paper plates, and so I made it and [he] and I sat down and just a couple times we did this very simplistic, probably like at a kindergarten level, and even this morning he seemed to get it but he was getting frustrated so we only did it for just probably half an hour tops… (participant 07)

Utility of a Psycho-educational Group

The second research question was in what ways can a support/psycho-educational group facilitate the parenting of children suspected to have FASD? The findings to address the second research question were very limited. The quantitative measures (i.e., Parenting Sense of Competence scale) did not capture any viable data. Some of the questions were poorly worded (e.g., asked two questions at once). The wording of the questions required an advanced reading level making comprehension difficult. Therefore, the data used to address the effectiveness of the psycho-educational group came solely from participants' journals. Questions referring to the effectiveness of the psycho-educational group were answered by four participants and spanned ten journals entries; two participants provided eight of the journal entries. Parents highlighted ways in which the psycho-educational group was beneficial. Many parents explained that having the time to talk with parents and share experience normalized the struggles of parenting a child with suspected FASD. Being part of a group with common challenges helped participants feel less alone and isolated. Other parents commented that the group served as a good reminder of skills and information that had already been learned. For example, the group reminded parents that it was important to remember that the child is not choosing to misbehave. In many instances the child could not actually understand and/or carry out instructions successfully. In addition, the group reminded parents to also focus on the daily positive interactions that occurred with their child. Being prompted by the group to highlight the positives and not just focus on the challenges was seen as beneficial and encouraging. Finally, parents commented that being reminded to focus on their needs was helpful. Making self-care a priority (e.g., going to the gym) enhanced parents' feelings of wellbeing and made it easier to cope with the daily challenges of parenting.

The beneficial aspects of the group not withstanding parents also highlighted some ways in which the group could have been improved. Parents explained that they would like more handouts and resources to enhance their parenting. However, parents did not like spending time reviewing these handouts in detail, preferring to read the material on their own time. In addition, parents talked about wanting the handouts to include a summary of what their children were learning so that it would be possible to see how the content of the children's and parents' group was complementary.

Some parents also expressed frustration over how the time spent in the group was allocated. Specifically, there was a desire to spend more time talking with fellow parents and less time doing opening activities where the parents and children spend time together. Other parents were sad when the group did not function properly because of poor attendance. Poor attendance was disappointing because parents lost out on the chance to interact with fellow group members. Parents were also disappointed for their children who had been looking forward to the social interactions provided by the group.

Biological and foster parents had different psycho-educational needs. For example, in this study, biological parents wanted to learn how to help manage their child's confrontational behaviour; foster parents wanted to focus on skills such as how to modify the environment to minimize situational dangers. As such, offering separate groups for biological and foster parents has the potential to be beneficial. In an effort to meet the distinct needs of biological and foster parents the group facilitator attempted to offer two separate groups. However, one group had poor attendance. In the end only one group was offered.

Personal Journal

My personal journal had an important impact on my analysis and the creation of the findings. My strengths based approach meant that I consistently highlighted parents' resilience and creativity while analyzing the data. The emphasis on strengths served to honor the many skills that parents of children with suspected FASD possessed. Furthermore, the journal allowed me to identify my bias towards parents having a sense of hope. This bias originated from the fact that my parents have always demonstrated a sense of hope and optimism when helping me cope and adapt to my physical disability. Moreover, the journal allowed me to appreciate how underprepared academics can be to comprehend parents' lived experiences. A key example of this can be seen in my expectation that the quantitative scales would provide useful information. As the research progressed I was continuously humbled by how little I understood about parenting a child with suspected FASD, despite having read the relevant academic literature. Also, the journal allowed me to appreciate how diverse the experiences of parents can be. While there are many key commonalities, recording my observations and reflections captured just how unique each parents lived experience was. I found myself engaging in a form of constant self-reflection that was similar to the self-reflection used by the parents.

Chapter Four provided a detailed overview of the findings as they pertain to the daily challenges of parenting a child with FASD and parents' experiences of these challenges. The findings also summarized feedback from parents who attended a psycho-educational group and whose children were on a waitlist for a FASD assessment. Chapter Five will provide a discussion of the findings, linking the data generated by the current study to existing literature. Implications for counselling, future research, and healthcare services will also be discussed.

Chapter 5

Discussion

The discussion links the findings of the current study to other research pertaining to parenting children with diagnosed FASD. The current study is integrated with literature on diagnosed FASD because an extensive literature search revealed no existing research focusing on suspected FASD. Commonalities and discrepancies between the current research and the existing body of research are highlighted. The discussion is organized around the larger themes of challenging environments, child's impaired cognitive functioning, other medical conditions, seeking to facilitate the child's independence, child's confrontational attitude, and the meta-themes. Implications for programming and counselling services are considered. Furthermore, the limitations of the current study and the need for future research are examined.

Challenging Environments

The findings related to insufficient supports for the child and parents not feeling heard by professionals are consistent with existing research on parenting children with diagnosed FASD. In the current study, parents of children with suspected FASD spent considerable time trying to secure adequate resources for their child. The absence of supports perpetuated feelings of frustration and anger. Parents derived considerable satisfaction and pride from making progress towards securing services for their child. These findings are consistent with Green's (2007b) research which noted that parents' distress comes primarily from setting up services for their child. Parents of children with suspected FASD in the current study worried about the challenges (e.g., learning difficulties) that were being made worse by a lack of services within the school system. Previous research has shown that a formal diagnosis and the services that accompany the diagnosis help to mediate the occurrence and severity of secondary disabilities (e.g., Streissguth et al., 1996; Swart, 2012). Malbin (2002) has also noted that learning strengths (e.g., experiential learning) can become diminished if proper supports, including adapted assignments, are not in place to promote these strengths.

In the current study, parents' struggles to access services were related to the fact that parents did not feel heard by professionals. Parents talked about feeling judged and angry because, from their perspective, professionals did not comprehend the experience of parenting a child with suspected FASD. Shepard and O'Neill (2012) noted that when caregivers felt understood by professionals it was easier to engage in a collaborative relationship where challenges could be examined through frank discussions of what was and was not effective. Additional research has also suggested that medical staff can benefit from the knowledge of adults with FASD and their caregivers (Harriman, 2007). Unfortunately, the insight of caregivers is frequently underutilized by professionals (Green, 2007b). Taken together this information suggests that ongoing efforts need to be made to enhance collaboration between health care professionals and parents of children with suspected FASD.

Challenges related to multiple adults trying to parent the child were reflected in the existing research on parenting children with diagnosed FASD. In the current study, foster parents of children with suspected FASD talked about working to ensure that the child's biological parents were involved in the child's life. Despite wanting their involvement, foster parents reported experiencing fear and disbelief because, in their opinion, the biological parent often struggled to look after the child without supervision. Foster parents' desire to have the biological parents involved in the child's life is consistent with Shepard and O'Neill's (2012) observation that regardless of the disagreements related to how the child should be parented, foster and adoptive parents considered maintaining contact with biological parents as vital to the child's wellbeing. The findings suggest that interventions that promote successful cooperation between biological parents and foster or adoptive parents may benefit the child with suspected FASD.

Interestingly, the challenge of regulating the child's use of video games is not documented in the existing research on parenting a child with diagnosed FASD. In the current study some parents used video games as a way to promote skills development. Other parents found that violent video games (e.g., Grand Theft Auto) perpetuated problematic behaviour such as swearing. However, games that promoted collaboration (e.g. The Lego series) can facilitate adaptive behaviour such as cooperating with others. The findings of the current study seem to suggest that when used correctly video games can enhance efforts to parent the child by promoting adaptive behaviour through modeling. Technology has been used successfully in other clinical applications such as phobias where people used video games to lessen their fear through virtual exposure (Botella, et al., 2011). There is also evidence to suggest that biofeed-back and brain-training exercises could help increase the child's concentration (Hallman, 2012). Video games could be constructed to meet multiple purposes, such as modeling behaviour and promoting concentration. The potential to use video games as a way to facilitate the parenting of children with suspected FASD is discussed under research implications.

The challenges of social isolation and the consequences of bullying were partially consistent with existing research. In the current study parents of children with suspected

FASD were concerned and frustrated by the prospect that their child could become socially isolated as their peers became older. Taking steps to avoid or reduce social isolation by developing the child's social skills was vital to parents. Brown and Bednar (2004) also found that parents of children with diagnosed FASD wanted their children to be included in events, such as school activities. Parents of children with diagnosed FASD noted that their child was not invited to social gatherings (e.g., birthday parties), had trouble finding age appropriate friends, and became isolated because of the stigma surrounding their FASD. None of the existing research seems to directly reflect the current study's findings around parents' concerns related to their child being bullied. However, Gardner (2000) found that parents of children with FASD feared their child would be manipulated and placed in unsafe situations by peers. These situations could potentially involve or lead to situations where the child is bullied.

In the present study, setbacks related to social interactions included being fearful over how the child would interact with peers. In line with other research (e.g., Gardner, 2000), parents in the current study feared that their child would be exploited by peers. Other parents worried that the way their child interacted with peers would prevent the development of supportive friendships. The concerns around the child's actions serving as a barrier to peer relationships is consistent with Whitehurst's (2012) study that found parents expressed concern related to how their child interacted with other children. In the current study, parents also commented that they worried about their child's ability to make life choices. A desire to see children with FASD make their own choices as adults is consistent with research by Michaud and Temple (2013) where parents of children with diagnosed FASD also worried about how to help their child become accustomed to making independent choices. Fostering good social and decision making skills could not only enhance the child's immediate social interactions but also move the child closer to making sound life choices in adulthood.

Child's Impaired Cognitive Functioning

Present research highlights the stresses of parenting a child with disruptive behaviours (e.g., Paley et al., 2006). Parental distress related to a child's cognitive impairments has been observed in the more general literature on caring for a child with mental delays (e.g., Neece, 2014). However, the existing research on FASD does not appear to capture parents' experience of feeling depressed and anxious over having to witness their child struggle because of their cognitive deficit. The daily challenges of helping the child regulate their anger when it is very hard to complete homework appear to be absent from the research. Consistent with the current study, other research has captured parents' desire to do everything they can to help their child (e.g., Zabitoka, 2012). In addition, the need to constantly remind the child to think about the consequences of their actions is consistent with the challenges identified by Devrise and Waller (2004). The current study appears to enhance the existing research by elucidating a deeper understanding of the daily issues that arise when parents are helping their child come to terms with cognitive limitations.

The findings in the present study that highlight parents' efforts to help their child with suspected FASD understand information are consistent with findings of other studies. FASD can be associated with various comprehension problems (e.g., Chudley et al., 2005; Jirikovic et al., 2008; Kerns et al., 1997; Timler et al., 2005; Zabitoka, 2012). The current study on suspected FASD highlights the ingenuity and resourcefulness of parents. Despite feeling anxious and angry and having few formal supports, parents found ways to enhance the child's understanding. The current study provides insight into some of the creative solutions used by parents, such as providing information in different modalities (e.g., using spoken and written instructions).

In the current study, some children with suspected FASD found change hard. The argument could be made that the cognitive impairments associated with FASD contribute to children struggling with change. The FASD literature does address helping children cope with change. Within the school system teachers have had to help children with FASD cope with changes to their medications and home environment (e.g., change in the caregiver; Clark et al., 2014). The current study suggests that while helping the child accept change can be challenging at first, with patience and various skills the child can come to not only accept but also enjoy change. Making parents even more aware of how to support their child through change may help provide new skills and strategies.

Parents in the current study feared that their child would be harmed because of their difficulty identifying when a situation is unsafe, a finding that is reflected in the existing literature (e.g., Gardner, 2000; Rutman & Van Bibber, 2010). Furthermore, parents in the current study worried that their child was too friendly and trusting, increasing the risk of being abused by strangers. Rutman and Van Bibber (2010) found that FASD can impair a person's ability to determine if people can be trusted. Given the potential for physical injury and/or abuse there is a need to help parents address their child's ability to gauge safety.

Other Medical Conditions

Parents talked about the stress and anger associated with managing their child's comorbid medical conditions in addition to the suspected FASD. Prenatal alcohol exposure has the potential to produce various medical conditions in addition to FASD (Barr et al. 1990; Becker et al., 1990; Burd et al., 2003; Church & Kaltenbach, 1997). The fact that some of the comorbid medical conditions mentioned in the current study had the potential to cause permanent damage (e.g., seizures) and were very distressing to parents highlights the need for an increased understanding of parents' knowledge or concerns and collaboration with health professionals.

Seeking to Facilitate the Child's Independence

Parents' efforts to help their child with suspected FASD solve problems and take responsibility for their actions is consistent with existing research. Parents in the current study were fearful that their child may require lifelong assistance and the task of helping the child become as independent as possible could be exhausting. Concerns about independence and trying to secure lifelong care are consistent with the findings of other studies (e.g., Caley et al., 2009; Streissguth et al., 1997, 2004). Moreover, parents in the current study talked about utilizing informal supports such as friends and family when raising the child which is also reflected in the literature (Brown & Bednar, 2003). Parents in the present study identified several challenges related to helping the child solve problems and take responsibility, including doing laundry. Nonetheless, these parents, similar to those in other studies (Michaud & Temple, 2013), remained committed and optimistic about making progress.

In the current study participants also talked about working to reduce the child's dependence on the parent. In keeping with other research (e.g., Michaud & Temple 2013) parents were sometimes unsure of how to start fostering independence while also being there to support the child when required. The current study also noted that parents frequently changed the environment to meet the child's needs rather than expecting the child to change. Changing the environment is a strategy that has been used by parents of children with diagnosed FASD (e.g., Buxton, 2004; Dorris, 1989; Malbin, 2007; Michaud &Temple 2013). Reducing dependence appears to require considerable time when FASD is involved. As such, working on independence skills from an early age could dramatically improve the success of independence later in the child's life.

Parents of children with suspected FASD spent a considerable amount of time helping their child self-regulate. Similar to parents in other studies (e.g., Salmon, 2007; Streissguth et al., 1997), parents in this study feared that their child's lack of self-regulation would result in the child becoming involved in altercations. In the current study parents dealt with not always knowing why a child was struggling with self-regulation and were frustrated by the fact that ways to assist the child were limited. Parents have described obtaining an increased understanding of their child's needs and a feeling of relief when a formal diagnosis is received (Shepard & O'Neill, 2012). One aspect of the present study that appears to be unique is the finding that some parents coped with a constant worry that progress was short-term. The current research does not seem to fully capture this constant state of flux where making progress is important but the unpredictable nature of FASD can make maintaining gains a constant challenge.

Child's Confrontational Attitude

In the current study, some parents of children with undiagnosed FASD had to deal with their child being verbally disrespectful. The FASD literature does mention instances of children with FASD talking back to their teachers (Streissguth et al., 1996). Also, previous studies emphasize the utility of skills used by parents in the current study, such as making the child aware of consequences (DeVries & Waller, 2004), and changing the environment, (Michaud & Temple, 2013). The present study shows that verbal disrespect can occur independent of the child displaying physical aggression. As such, there may be a need to specifically investigate instances of children with suspected FASD using verbal disrespect. A deeper understanding of this daily challenge could generate new skills and strategies for parenting these children.

Some parents in the current study expressed fear and anxiety related to their child's physical aggression. Concerns stemmed from the fact that the reason for the aggression was not always known; parents were unsure of how to manage the aggression as their child became older and stronger. Fears related to not being able to manage the child's physical aggression are congruent with the concerns caregivers have around trying to restrain a large child (Caley et al., 2009). Michaud and Temple (2013) also found that parents sometimes had to ask the child to leave the home because of aggressive behaviour. Being unable to manage the child's aggressive actions left parents feeling guilty, and there was a sense of failure over being unable to continue parenting the child. The findings of the current study and previous research suggest that additional supports are needed to facilitate parents' desire to continue raising their child.

Meta Themes

Parents' sense of hope that progress was possible based on past successes shares similarities with other aspects of FASD and hope research. Brown and Bednar (2003) have found that a sense of hope is essential when parenting a child with diagnosed FASD. Even when confronted by the realization that their child with diagnosed FASD may not be able to reach developmental milestones, parents remained hopeful that change and progress were possible (Watson et al., 2013). Research looking at hope, in general, has shown that hope can foster a sense of empowerment (e.g., Cutcliffe, 2004). Furthermore, hope can produce motivation associated with goal directed behaviour, and plans to achieve goals (Snyder, Irving, & Anderson, 1991). The literature would suggest that a sense of hope can increase parents' motivations and feelings of self-efficacy, making it easier to persevere in spite of ongoing challenges. Hope may also serve as a protective factor, lowering parental stress when their child has a chronic condition. Hope has been found to help lower parental stress when caring for a young child with diabetes (Mednick et al., 2007). There is a need to investigate whether or not the advantageous effects of hope also apply when raising a child with other chronic conditions, such as suspected FASD.

Parents' frequent use of self-reflection, while not mentioned in the FASD research, is referenced in the general parenting literature. Self-reflection has been identified as a mechanism by which parents can examine the assumptions they hold about parenting and begin to change their parenting style as required. Self-reflection provides a mechanism for coming up with new solutions to challenges and realizing what parents can realistically expect of themselves (Ireland, 1992). Given that self-reflection can facilitate enhanced parenting, generally speaking, it makes sense to foster this skill in parents whose children have suspected FASD.

In the current study, seeking to understand their child's perspective made it easier for parents to remain patient. Furthermore, the enhanced understanding parents derived from looking at situations from their child's point of view often generated new strategies or solutions to challenges. The existing FASD literature does mention the benefits of parents developing new perspectives (e.g., understanding that the child is not at fault; Shepard & O'Neill, 2012). The benefits of seeing situations from another person's point of view are also supported by the more general literature. When people feel that their situation is understood by another person, these people experience an increased sense of closeness and willingness to help each other. Taking the perspective of another person also promotes empathy (Goldstein, Vezich, & Shapiro 2014). The increased feelings of closeness and desire to help might explain parents' love for their child and desire to help them regardless of the challenges that are encountered. The empathy generated by looking at situations from the child's perspective may explain why parents talked about having more patience after having considered their child's point of view. Encouraging parents to look at situations from their child's point of view may help parents persevere and remain patient, despite facing considerable ongoing obstacles.

Parents' constant use of flexibility and creativity as a way to cope with the fact that each child and situation often required a different strategy is reflected in the existing FASD literature. Brown and Bednar (2003) found that parents of children with diagnosed FASD advocated for flexible services that could meet each family's unique situation and complement existing resources. Parents also emphasized that the ability to be flexible was vital when parenting their child. The utility of flexibility and creativity is also supported indirectly through the acknowledgement that symptoms of FASD can be diverse, and include physical, mental, behavioural and learning issues (Chudley et al., 2005). The fact that a child with suspected FASD could have any combination of these impairments, which have yet to be identified, speaks to the need for parents to be flexible and utilize ingenuity.

Implications for Programming and Counselling

The findings of the current study have several implications at the programming level. Parents of children with suspected FASD have demonstrated a tremendous resilience and willingness to learn. Regardless of the challenge in question, parents never stopped searching for new resources or skills. Johnston and Boyle (2013) observed that parents in northern aboriginal communities constantly strove to develop new skills, even in the absence of formal supports. Parents of children with suspected FASD have demonstrated that there is a desire to utilize every opportunity to learn. Organizations and governments should facilitate parents' efforts to learn by offering formal interventions. Parents in the current study are seeking collaborative relationships with health professionals.

Services such as counselling for parents of children with suspected FASD could benefit from nurturing helpful mindsets, such as a sense of hope, creativity, flexibility and ongoing self-reflection. Counsellors should also consider helping parents see situations from their child's point of view, since this shift in perspective seems to promote patience and the creation of new solutions for challenges.

Given that biological and foster or adoptive parents can have different needs (Shepard & O'Neill, 2012), it makes sense to offer separate psycho-educational groups for each set of parents. Having different groups would allow the facilitator to offer resources and skills that are most pertinent to each group, potentially helping to maximize the effectiveness of the psycho-educational group. However, it is also important to promote collaboration and interaction between biological parents, foster parents and adoptive parents; working collaboratively can help biological parents feel less judged (Shepard & O'Neill, 2012). The requirement to refine the psycho-educational group so that the focus is more on the interactions between parents is consistent with the finding that a sense of being connected to people facing similar struggles is vital. Parents of children with diagnosed FASD find sharing their experiences and skills helps them feel less alone (Shepard & O'Neill, 2012). Also, the importance of making the group fluid enough to meet the needs of the specific families involved (e.g., more handouts and less time spent on parent-child interactions) is in keeping with Brown and Bednar (2003), who found that parents wanted individualized services. Finally, the challenges identified in the current study (i.e., challenging environments, child's cognitive impairment, child's other medical conditions, seeking to facilitated the child's independence and, the child's confrontational attitude) can serve as targets for the development of skills and interventions for parents of children with suspected FASD. Helping parents become even more adept at managing these challenges has the potential to reduce the stress associated with waiting for a diagnosis and decrease the development of secondary disabilities.

Specifically, helping parents guide their children through challenges such as social isolation and consequences of bullying might help children develop more extensive and positive peer relationships. Having a robust social network might help lower the child's frustration and promote an enhanced quality of life. Furthermore, having support networks that extend beyond the family could help elevate some of the concerns around who can help support the child as they mature and move into adulthood. A social network is intended to supplement, not reduce, the need for formal supports throughout the child's life. These potential benefits are only speculative, but nonetheless are worthy of consideration and exploration.

Research Implications

Perhaps the most promising research area related to the present study is the use of video games to promote adaptive behaviour (e.g., cooperation) in children with suspected FASD. There is existing research to support the use of video games as a therapeutic tool; video games have been able to help clients overcome their phobias (e.g., cockroaches).

Importantly, clients reported that, in their opinion, the video game produced gains independent of other treatments such as in vivo exposure (Botella et al., 2011). The potential to use video games to reduce the child's maladaptive behaviour is also supported by the fact that existing games such as the Lego series appear to facilitate social behaviour. New technology also makes it possible to combine computer generated images with a person's actual environment (Azuma, 1997). This software could allow children to play through games that promote positive behaviours in real life settings, such as the child's home or school. Parents in the current study commented that their child spent a considerable amount of time playing video games. Being able to merge a therapeutic intervention with an already enjoyable activity could produce behavioral changes, without placing additional demands on the parents or their child.

The fact that only two participants completed multiple journals highlights the need to refine this form of data collection. Efforts to make the journals more accessible by allowing parents to record their spoken responses were not very effective; parents with lower written skills also tended to be less comfortable with using technology (i.e., the computer program used to record their spoken responses). There may be a desire to look at an automated system where parents phone in and speak their responses following automated prompts. Using a phone based system would remove the task of asking parents to learn how to use a new piece of technology. However, it is important to note that a lack of time either precluded parents from agreeing to do the journals or meant that the parents doing the journals missed entries. The numerous ongoing demands on parents' time may render the use of a weekly journal system too demanding for the majority of parents.

In addition to the research implications related specifically to the current study, there are other topics that warrant future exploration. There is a need to develop quantitative measures that can assess the effectiveness of interventions, such as the psycho-educational group. Examining the daily challenges of parenting a child with suspected FASD across different cultures (e.g., individualistic vs. collectivist) may yield different experiences. Parents themselves can be coping with FASD while raising their child with suspected FASD; other studies could explore the experience of parenting a child with suspected FASD when the parent also has FASD. The current study and future research opportunities highlight the potential for innovative work that directly benefits families and communities.

Limitations of the Study

There are several limitations inherent in the current study. There were a disproportionate number of foster or adoptive parents relative to biological parents. This disparity made it impossible to explore, in depth, how different types of parents may vary in their experiences of parenting. Given the many demands on parents' time, it was difficult to follow up with participants after the first interview. The issues related to having participants check the accuracy of the analysis was addressed by having the findings vetted by two experienced clinicians. Although, having two clinicians check the data was not the same as member checking, in the absence of extensive member checking, having the information reviewed by experienced professionals was the next best option. The absence of extensive member checking remains a methodological weakness. The study did not account for cultural differences, as most of the participants were Caucasian. The majority of participants were female, making it impossible to explore potential gender differences related to the daily experiences of parenting. Some of the challenges faced by parents may also be partly due to other issues such as the child's attachment style (Cassidy & Shaver, 2008) and not the suspected FASD.

Having only two parents complete multiple weekly journals, combined with the lack of viable quantitative data, restricted the study's ability to address the effectiveness of the psycho-educational group. As outlined in the research implications, the weekly journal system needs refinement. Given the many demands parents of children with suspected FASD face, asking parents to complete a weekly journal may be too time consuming regardless of the format that is used. The limitations of the current research notwithstanding, the findings provide a foundation for future research related to parenting a child with suspected FASD.

Conclusions

The thesis looked at two related but distinct questions: (a) What types of challenges do parents of children with suspected but not yet diagnosed FASD face on a daily basis and how do parents experience those challenges? (b) In what ways can a support/psycho-educational group facilitate the parenting of children suspected to have FASD? Learning about the daily experiences of parents whose children have suspected FASD has been a rewarding and humbling experience. I am honored to have witnessed the strength and determination of these parents. Having grown up with a physical disability I have some firsthand knowledge of the vital role played by parents with respect to advocating for services for their child, finding creative ways to help their children overcome barriers, and seeking to ensure that their child has the most independent life possible. I am also impressed by the fact that parents have identified the types of supports and interventions that are needed. The academic and professional community should take steps to learn from parents of children with suspected FASD rather than seeking to prescribe interventions and supports.

References

Abel, E. L. (1995). An update on incidence of FAS: FAS is not an equal opportunity birth defect. *Neurotoxicology and Teratology, 17*(4), 437-443.

Abel, E. L., & Hannigan, J. H. (1995). 'J-shaped' relationship between drinking during pregnancy and birth weight: Reanalysis of prospective epidemiological data. *Alcohol and Alcoholism, 30*(3), 345-355.

Alleman, J., R. (2002). Online counselling: The internet and mental health treatment. *Journal of Psychotherapy: Theory, Research, Practice and Training, 39*(2), 199-209. doi: 10.1037//0033-3204.39.2.199

Azuma, R. T. (1997). A survey of augmented reality. *Presence: Teleoperators and Virtual Environments, 6*(1), *355–385.*

Badry, D., & Wight Felske, A. (2013). An examination of three key factors: Alcohol, trauma and child welfare: Fetal alcohol spectrum disorder and the northwest territories of Canada. *First Peoples Child & Family Review, 8*(1), 131-143.

Baer, J. S., Sampson, P. D., Barr, H. M., Connor, P. D., & Streissguth, A. P. (2003). A 21-year longitudinal analysis of the effects of prenatal alcohol exposure on young adult drinking. *Archives of General Psychiatry, 60*(4), 377-385. doi: 10.1001/archpsyc.60.4.377

Barr, H. M., Streissguth, A. P., Darby, B. L., & Sampson, P. D. (1990). Prenatal exposure to alcohol, caffeine, tobacco, and aspirin: Effects on fine and gross motor performance in 4-year-old children. *Developmental Psychology, 26*(3), 339-348. doi: 10.1037/0012-1649.26.3.339

Becker, M., Warr-Leeper, G., & Leeper, H. A., J. (1990). Fetal alcohol syndrome: A description of oral motor, articulatory, short-term memory, grammatical, and semantic abilities. *Journal of Communication Disorders, 23*(2), 97-124.

Beckman, P. J. (2002). Providing family-centered services. In M. Batshaw (Ed.), *A medical primer* (pp. 683-691). Baltimore, MD: Paul H. Brookes.

Bingol, N., Schuster, C., Fuchs, M., Iosub, S., Turner, G., Stone, R. K., & Gromisch, D. S. (1987). The influence of socioeconomic factors on the occurrence of fetal alcohol syndrome. *Advances in Alcohol & Substance Abuse, 6*(4), 105-118. doi: 10.1300/J251v06n04_08

Blackburn, C., Carpenter, B., & Egerton, J. O. (2010). Shaping the future for children with foetal alcohol spectrum disorders. *Support for Learning, 25*(3), 139-145. doi: 10.1111/j.1467-9604.2010.01452.x

Boland, F., Chudley, A., & Grant, B. (2009). *Forum on corrections research. Correctional Services Canada*. Retrieved April 2, 2013 from www.csc- scc.gc.ca.

Botella, C., Breton-López, J., Quero, S., Baños, R. M., García-Palacios, A., Zaragoza, I., & Alcaniz, M. (2011). Treating cockroach phobia using a serious game on a mobile phone and augmented reality exposure: A single case study. *Computers in Human Behavior, 27*(1), 217-227. doi:10.1016/j.chb.2010.07.043

Boydell, K. M., Pong, R., Volpe, T., Tilleczek, K., Wilson, E., & Lemieux, S. (2006). Family perspectives on pathways to mental health care for children and youth in rural communities. *Journal of Rural Health, 22*(2), 182-188.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. doi: http://dx.doi.org/10.1191/1478088706qp063oa

Brown, J. D., & Bednar, L. M. (2003). Parenting children with fetal alcohol spectrum disorder: A concept map of needs. *Developmental Disabilities Bulletin, 31*(2), 130-154.

Brown, J. D., & Bednar, L. M. (2004). Challenges of parenting children with a fetal alcohol spectrum disorder: A concept map. *Journal of Family Social Work, 8*(3), 1-18.

Brown, J. D., Sigvaldason, N., & Bednar, L. M. (2005). Foster parent perceptions of placement needs for children with a fetal alcohol spectrum disorder. *Children and Youth Services Review, 27*(3), 309-327. doi: 10.1016/j.childyouth.2004.10.008

Brown, J., Sigvaldason, N., & Bednar, L. (2007). Motives for fostering children with alcohol-related disabilities. *Journal of Child & Family Studies, 16*(2), 197-208. doi: 10.1007/s10826-006-9078-1

Bryan, J. (2005). Fostering educational resilience and achievement in urban schools through school-family-community partnerships. *Professional School Counseling, 8*(3), 219-227.

Burd, L., Cotsonas-Hassler, T. M., Martsolf, J. T., Kerbeshian, J. (2003). Recognition and management of fetal alcohol syndrome. *Neurotoxicology and Teratology, 25*(6), 681-688. doi: http://dx.doi.org/10.1016/j.ntt.2003.07.020

Burd, L., Martsolf, J. T., Klug, M. G., & Kerbeshian, J. (2003). Diagnosis of FAS: A comparison of the fetal alcohol syndrome diagnostic checklist and the institute of medicine criteria for fetal alcohol syndrome. *Neurotoxicology and Teratology, 25*(6), 719-724. doi: 10.1016/j.ntt.2003.07.015

Burgess, D., & Streissguth, A. (1990). Educating students with fetal alcohol syndrome or fetal alcohol effects, *Pennsylvania Reporter, 22*(1), 1-3.

Burstyn, I., Sithole, F., & Zwaigenbaum, L. (2010). Autism spectrum disorders, maternal characteristics and obstetric complications among singletons born in Alberta, Canada. *Chronic Diseases in Canada, 30*(4), 125-134. Retrieved from http://www.phac-aspc.gc.ca/publicat/cdic-mcbc/30-4/PDF/Vol30n4_Article02-eng.pdf

Buxton, B. (2004). *Damaged angels: A mother discovers the terrible cost of alcohol in pregnancy.* Toronto, Canada: Random House.

Caley, L. M., Winkelman, T., & Mariano, K. (2009). Problems expressed by caregivers of children with fetal alcohol spectrum disorder. *International Journal of Nursing Terminologies and Classifications: The Official Journal of NANDA International, 20*(4), 181-188. doi: 10.1111/j.1744-618X.2009.01133.x

Canadian FASD Research Network (2013). Diagnostics. Retrieved from http://www.canfasd.ca/research-teams/diagnostics/

Canadian FASD Research Network (2014). Prevalence. Retrieved from http://www.canfasd.ca/research-teams/prevalence/

Cassidy, J., & Shaver, P. R. (Eds.). (2008). *Handbook of attachment: Theory, research, and clinical applications*. New York, NY: Guilford.

Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ: Canadian Medical Association Journal Supplement, 172*(5), S1-S21.

Church, M. W., & Kaltenbach, J. A. (1997). Hearing, speech, language, and vestibular disorders in the fetal alcohol syndrome: A literature review. *Alcoholism, Clinical and Experimental Research, 21*(3), 495-512.

Clark, E. (2003). *Community integration and independence among adults with Fetal Alcohol Spectrum Disorder in British Columbia.* Unpublished manuscript, Queen's University at Kingston, Kingston, ON.

Clark, E., George, M., Hardy, C., Hall, W., MacMillan, P., Wakabayashi, S., & Hughes, K. (2014). Exploratory study of the effectiveness of a professional development program on the academic achievement and classroom behavior of students with Fetal Alcohol Spectrum Disorder in British Columbia, Canada. *The International Journal Of Alcohol And Drug Research, 3*(1), 25-34. doi:http://dx.doi.org/10.7895/ijadr.v3i1.119

Clark, E., Lutke, J., Minnes, P., & Ouellette-Kuntz, H. (2004). Secondary disabilities among adults with Fetal Alcohol Spectrum Disorder in British Columbia. *Journal of Fetal Alcohol Syndrome International. 2*(13), 1-12.

Clarren, S., Olson, H. C., Clarren, S. G., & Astley, S. (2000). A child with fetal alcohol syndrome. In M. Guralnick (Ed.). *Interdisciplinary clinical assessment of young children with developmental disabilities* (pp. 307-326). Baltimore, MD: Paul H. Brooks.

Coles, C. D. (2003). Individuals affected by fetal alcohol spectrum disorder and their families: Prevention, intervention, and support. In R. E. Tremblay, R. G. Barr, RDeV. Peters, (Eds.), *Encyclopedia on early childhood development* [online]. Retrieved December 3, 2011, from http://www.child-encyclopedia.com/documents/ColesANGxp.pdf.

Connor, P. D., Sampson, P. D., Bookstein, F. L., Barr, H. M., & Streissguth, A. P. (2000). Direct and indirect effects of prenatal alcohol damage on executive function. *Developmental Neuropsychology, 18*(3), 331-354. doi: http://dx.doi.org/10.1207/S1532694204Connor

Cutcliffe, J. (2004). *The inspiration of hope in bereavement counselling.* London, United Kingdom: Jessica Kingsley.

Davis, D. (1996). For parents and counselors with adolescents and adults with FAS/FAE. *Reaching out to children with FAS/FAE.* New York, NY: Simon & Shuster.

Denys, K., Rasmussen, C., & Henneveld, D. (2011). The effectiveness of a community-based intervention for parents with FASD. *Community Mental Health Journal, 47*(2), 209-219. doi: 10.1007/s10597-009-9273-9

DeVries, J., & Waller, A. (2004). Fetal alcohol syndrome through the eyes of parents. *Addiction Biology, 9*(2), 119-126. doi: http://dx.doi.org/10.1080/13556210410001716971

Dorris, M. (1989). *The broken cord.* New York, NY: Harper & Row.

Dube, S. R., Anda, R. F., Felitti, V. J., Edwards, V. J., & Williamson, D. F. (2002). Exposure to abuse, neglect, and household dysfunction among adults who witnessed intimate partner violence as children: implications for health and social services. *Violence and Victims, 17*(1), 3-17. doi: http://dx.doi.org/10.1891/vivi.17.1.3.33635

Duquette, C., & Stodel, E. J. (2005). School experiences of students with fetal alcohol spectrum disorder. *Exceptionality Education Canada, 15*(2), 51-75.

Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006). Teaching students with developmental disabilities: Tips from teens and young adults with fetal alcohol spectrum disorder. *Teaching Exceptional Children, 39*(2), 28-31.

Edmonds K., & Crichton, S. (2008). Finding ways to teach to students with FASD: A research study. *International Journal of Special Education, 23*(1), 54-73.

Eiden, R. D. (2001). Maternal substance use and mother–infant feeding interactions. *Infant Mental Health Journal, 22*(4), 497-511. doi: http://dx.doi.org/10.1002/imhj.1013

Eiden, R. D., Peterson, M., & Coleman, T. (1999). Maternal cocaine use and the caregiving environment during early childhood. *Psychology of Addictive Behaviors, 13*(4), 293-302. doi:10.1037/0893-164X.13.4.293

Famy, C., Streissguth, A. P., & Unis, A. S. (1998). Mental illness in adults with fetal alcohol syndrome or fetal alcohol effects. *The American Journal of Psychiatry, 155*(4), 552-554.

Festinger, L. (1962). *A theory of cognitive dissonance*. Stanford, CA: Stanford University.

Foucault, M. (1979). *Michel Foucault: Power, truth, strategy*. Ann Arbor, MI: Feral.

Galassi, J., & Akos, P. (2007). *Strengths-based school counseling: Promoting student development and achievement*. Mahwah, NJ: Lawrence Erlbaum.

Garcia-Lizana, F., & Muñoz-Mayorga, I. (2010). What about telepsychiatry? A systematic review. *The Primary Care Companion to the Journal of Clinical Psychiatry, 12*(2). doi:10.4088/PCC.09m00831whi

Gardner, J. (2000). Living with a child with fetal alcohol syndrome. *MCN: The American Journal of Maternal/Child Nursing, 25*(5), 252-257. doi: http://dx.doi.org/10.1097/00005721-200009000-00007

George, M. A., & Hardy, C. (2013). Addressing FASD in British Columbia, Canada: Analysis of funding proposals. *Journal of Population Therapeutics and Clinical Pharmacology, 21*(3), 338-345.

Gibson, K. L., Coulson, H., Miles, R., Kakekakekung, C., Daniels, E., & O'Donnell, S. (2011). Conversations on telemental health: Listening to remote and rural First Nations communities. *Rural and Remote Health, 11,* 1–19. Retrieved from http://www.rrh.org.au

Gibson, K., O'Donnell, S., Coulson, H., & Kakepetum-Schultz, T. (2011). Mental health professionals' perspectives of telemental health with remote and rural First Nations communities. *Journal of Telemedicine and Telecare, 17,* 263–267. doi:10.1258/jtt.2011.101011

Glaser, B., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.

Goldstein, N. J., Vezich, I. S., & Shapiro, J. R. (2014). Perceived perspective taking: When others walk in our shoes. *Journal of Personality and Social Psychology, 106*(6), 941-960. doi:10.1037/a0036395

Government of British Columbia. (2008). Fetal Alcohol Spectrum Disorder: Building on Strengths. A Provincial Plan for British Columbia 2008-2018. Retrieved from http://www.mcf.gov.bc.ca/fasd/pdf/FASD_TenYearPlan_WEB.pdf

Government of British Columbia. (2013). Keyworker and Parent Support Services. Retrieved from http://www.mcf.gov.bc.ca/fasd/kw_support.htm

Graefe, S. (1998). *Parenting children affected by fetal alcohol spectrum disorder: A guide for daily living*. Ottawa, Canada: Adoption Council of Canada.

Grant, T., Huggins, J., Connor, P., & Streissguth, A. (2005). Quality of life and psychosocial profile among young women with fetal alcohol spectrum disorders. *Mental Health Aspects of Developmental Disabilities, 8*(2), 33-39.

Green, J. H. (2007a). Fetal alcohol spectrum disorders: Understanding the effects of prenatal alcohol exposure and supporting students. *Journal of School Health, 77*(3), 103-108. doi: 10.1111/j.1746-1561.2007.00178.x

Green, S. E. (2007b). 'We're tired, not sad': Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163. doi: 10.1016/j.socscimed.2006.08.025

Habbick, B. F., Nanson, J. L., Snyder, R. E., Casey, R. E., & Schulman, A. L. (1995). Foetal alcohol syndrome in Saskatchewan: Unchanged incidence in a 20-year period. *Canadian Journal of Public Health, 87*(3), 204-207.

Hallman, D. W. (2012). 19-channel neurofeedback in an adolescent with FASD. *Journal of Neurotherapy, 16*(2), 150-154. doi: http://dx.doi.org/10.1080/10874208.2012.677646

Harriman, K. (2007). *Gifts, talents and challenges: Untapped potential of adults with FASD* (Master's thesis). Available from ProQuest Dissertation and Theses database. (UMI No. 304833773).

Harwood, M., & Kleinfeld, J. S. (2002). Up front, in hope: The value of early intervention for children with fetal alcohol syndrome. *Young Children, 57*(4), 86-90.

Health Canada. (2002). *Congenital anomalies in Canada — A perinatal health report*. Ottawa: Minister of Public Works and Government Services Canada. Retrieved from http://www.hc-sc.gc.ca/pphb-dgspsp/rhs-ssg/index.html

Hooper, S. R., Murphy, J., Devaney, A., & Hultman, T. (2000). Ecological outcomes of adolescents in a psychoeducational residential treatment facility. *American Journal of Orthopsychiatry, 70*(4), 491-500. doi: http://dx.doi.org/10.1037/h0087807

Ireland, S. E. (1992). *Furthering the practice of parent education: Developing skills of critical self-reflection in parenting programs* (Doctoral dissertation). Available from ProQuest Dissertation and Theses database. (UMI No. 303988874)

Jellinek, E. M. (1960). *The disease concept of alcoholism.* New Haven, CT: College and University Press.

Jennett, P. A., Hall, L. A., Hailey, D., Ohinmaa, A., Anderson, C., Young, B., . . . Scott, R. E. (2003). The socio-economic impact of telehealth: A systematic review. *Journal of Telemedicine and Telecare, 9*(6), 311–320. doi:10.1258/135763303771005207

Jirikovic, T., Olson, H. C., & Kartin, D. (2008). Sensory processing, school performance, and adaptive behavior of young school-aged children with fetal alcohol spectrum disorders. *Physical & Occupational Therapy in Pediatrics, 28*(2), 117-136. doi: http://dx.doi.org/10.1080/01942630802031800

Johnston, S., & Boyle, J., S. (2013). Northern British Columbian aboriginal mothers: Raising adolescents with fetal alcohol spectrum disorder. *Journal of Transcultural Nursing, 24*(1), 60-67. doi: 10.1177/1043659612452006

Jong, M. (2004). Managing suicides via videoconferencing in a remote northern community in Canada. *International Journal of Circumpolar Health, 63*(4), 422–428. doi:10.3402/ijch.v63i4.17759

Kerns, K., Don, A., Mateer, C. A., & Streissguth, A. P. (1997). Cognitive deficits in normal IQ and borderline IQ adults with fetal alcohol syndrome. *Journal of Learning Disabilities, 30*(6), 685-693. doi: 10.1177/002221949703000612

Kodituwakku, P. W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: A review. *Neuroscience and Biobehavioral Reviews, 31*(2), 192-201. doi: http://dx.doi.org/10.1016/j.neubiorev.2006.06.020

Kulig, C., J., & Williams, M., A. (Eds.) (2011). *Health in rural Canada.* Vancouver, Canada: UBC Press.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.

Madigan, S. (2011). *Narrative therapy.* Washington, DC: American Psychological Association.

Malbin, D. (1993). *Fetal alcohol syndrome, Fetal alcohol effects: Strategies for professionals.* Center City, MA: Hazelton Educational Materials.

Malbin, D. (2002). *Fetal Alcohol Spectrum Disorder. Trying differently rather than harder.* Portland, OR: Tectrice.

Malbin, D. V. (2007). *Fetal alcohol spectrum disorders: A collection of information for parents and professionals.* Portland, OR: FASCETS, Incorporated.

Masotti, P., George, M. A., Szala-Meneok, K., Morton, A. M., Loock, C., Van Bibber, M., Ranford, J., Fleming, M., & MacLeod, S. (2006). Preventing fetal alcohol spectrum disorder in aboriginal communities: A methods development project. *PLoS Medicine, 3*(1), e8-0029. doi:10.1371/journal.pmed.0030008

May, P. A., & Gossage, J. P. (2001). Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research & Health, 25*(3), 159-167.

May, P. A., Gossage, J. P., Marais, A., Adnams, C. M., Hoyme, H. E., Jones, K. L., . . . Viljoen, D. L. (2007). The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug and Alcohol Dependence, 88*(2-3), 259-271. doi: 10.1016/j.drugalcdep.2006.11.007

Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R. (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with type 1 diabetes. *Children's Health Care, 36*(4), 385-396. doi: http://dx.doi.org/10.1080/02739610701601403

Michaud, D., & Temple, V. (2013). The complexities of caring for individuals with fetal alcohol spectrum disorder: The perspective of mothers. *Journal on Developmental Disabilities, 19*(3), 94-101.

Miller, B. A., Downs, W. R., Gondoli, D. M., & Keil, A. (1987). The role of childhood sexual abuse in the development of alcoholism in women. *Violence and Victims, 2*(3), 157-172.

Murphy, L. J., & Mitchell, D. L. (1998). When writing helps to heal: E-mail as therapy. *British Journal of Guidance & Counselling, 26*(1), 21-32. doi: 10.1080/03069889800760031

Nanson, J. L., & Hiscock, M. (1990). Attention deficits in children exposed to alcohol prenatally. *Alcoholism: Clinical and Experimental Research, 14*(5), 656-661. doi: 10.1111/j.1530-0277.1990.tb01223.x

Nash, J. M. (2014). *Maternal sensitivity in mother-infant interactions for infants with and without prenatal alcohol exposure*ProQuest Information & Learning). *Dissertation Abstracts International: Section B: The Sciences and Engineering, 74*(11). (2014-99101-011)

Neece, C. L. (2014). Mindfulness-based stress reduction for parents of young children with developmental delays: Implications for parental mental health and child behavior problems. *Journal of Applied Research in Intellectual Disabilities, 27*(2), 174-186. doi: http://dx.doi.org/10.1111/jar.12064

NeuroDevNet, (2015). Strongest Families study recruiting for FASD study of behavioural coaching and resources. Retrieved http://www.neurodevnet.ca/news/strongest-families-study-recruiting-fasd-study-behavioural-coaching-and-resources/

Northern Health (2011a). Northern Health Assessment Network Program evaluation 2011. Retrieved from www.northernhealth.ca

Northern Health (2011b). Northern Health Assessment Network. Retrieved from http://www.northernhealth.ca/Portals/0/Your_Health/Programs/Public%20Health/NHAN/NH%20April%208%20enhancing%20communication.pdf

O' Malley, K. D., & Storoz, L. (2003). Fetal alcohol spectrum disorders and ADHD: Diagnostic implications and therapeutic consequences. *Expert Review of Neurotherapeutics, 3*(4), 477-489. doi: http://dx.doi.org/10.1586/14737175.3.4.477

O'Connor, M. J., Kogan, N., & Findlay, R. (2002). Prenatal alcohol exposure and attachment behavior in children. *Alcoholism: Clinical and Experimental Research, 26*(10), 1592-1602. doi: 10.1111/j.1530-0277.2002.tb02460.x

Ohan, J. L., Leung, D. W., & Johnston, C. (2000). The parenting sense of competence scale: Evidence of a stable factor structure and validity. *Canadian Journal of Behavioural Science/Revue Canadienne Des Sciences Du Comportement, 32*(4), 251-261. doi:10.1037/h0087122

Ollech, S. C. (2001). *Health, social and educational resources for children with FASFAE in two northern BC communities* (Master's thesis). Retrieved from https://wizard.unbc.ca/search/?searchtype=c&SORT=D&searcharg=RG629.F45O45+2001+&searchscope=3

Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews, 15*(3), 235-249. doi: http://dx.doi.org/10.1002/ddrr.65

Paley, B., O'Connor, M. J., Frankel, F., & Marquardt, R. (2006). Predictors of stress in parents of children with fetal alcohol spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 27*(5), 396-404. doi: 10.1097/00004703-200610000-00005

Pelech, W., Badry, D., & Daoust, G. (2013). It takes a team: Improving placement stability among children and youth with fetal alcohol spectrum disorder in care in Canada. *Children and Youth Services Review, 35*(1), 120-127. doi: http://dx.doi.org/10.1016/j.childyouth.2012.10.011

Ragsdale, J. (2006). *Interventions and supports for adults with fetal alcohol spectrum disorder :An integrative and interpretive review* (Master's thesis). Retrieved from https://wizard.unbc.ca/search~S3/?searchtype=c&searcharg=HV3005.R34+2006&searchscope=3&sortdropdown=&SORT=D&extended=1&SUBMIT=Search&searchlimits=&searchorigarg=cRG629.F45O45+2001+

Robinson, C., G., Conroy, L., J., & Conroy, R., R. (1987). Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in British Columbia. *CMAJ.Canadian Medical Association Journal, 137*(3), 203-207.

Rutman, D., & Van Bibber, M. (2010). Parenting with fetal alcohol spectrum disorder. *International Journal of Mental Health and Addiction, 8*(2), 351-361. doi: 10.1007/s11469-009-9264-7

Rutman, D., LaBerg, C., & Wheway, D. (2002). *Adults living with FAS/E: Experiences and support issues in British Columbia.* Victoria, BC: University of Victoria, FAS/E Support Network of BC.

Rutman, D., LaBerge, C., & Wheway, D. (2004) *Adults with FASD: Addressing the challenges of daily living – A research and video production project.* University of Victoria, BC: FAS/E Support Network of BC & The Research Initiatives for Social Change Unit, School of Social Work.

Salmon, J. (2007). Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *The Canadian Journal of Clinical Pharmacology, 15*(2), 191-213.

Sampson, P. D., Streissguth, A. P., Bookstein, F. L., Little, R. E., Clarren, S. K., Dehaene, P. C., ... Graham, J. M. (1997). Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. *Teratology, 56*(5), 317-326.

Sanders, J. L., & Buck, G. (2010). A long journey: Biological and non-biological parents' experiences raising children with FASD. *Journal of Population Therapeutics and Clinical Pharmacology, 17*(2), 308-322.

Shepard, B., & O'Neill, L. K. (2012). Intervention of hope: Sustaining caregivers of children with FASD through therapeutic psychoeducational camps. *Canadian Journal of Family and Youth, 4*(1), 79-108.

Smith, E. J. (2006). The strength-based counseling model. *The Counseling Psychologist, 34*(1), 13-79. doi: 10.1177/0011000005277018

Snyder, C. R., Irving, L. M., & Anderson, J. R. (1991). Hope and health. In C. R. Snyder & D. R. Forsyth (Eds.), *Handbook of social and clinical psychology: The health perspective* (pp. 285–305). New York, NY: Permagon Press.

Sokol, R. J. J., Delaney-Black, V., & Nordstrom, B. (2003). Fetal alcohol spectrum disorder. *JAMA: Journal of the American Medical Association, 290*(22), 2996-2999. doi: 10.1001/jama.290.22.2996

Spohr, H. L.,Willms, J., & Steinhausen, H. C. (2007). Fetal alcohol spectrum disorders in young adulthood. *Journal of Pediatrics, 150*(2), 175-179. doi: http://dx.doi.org/10.1016/j.jpeds.2006.11.044

Steinhausen, H., Willms, J., & Spohr, H. (1993). Long-term psychopathological and cognitive outcome of children with fetal alcohol syndrome. *Journal of the American Academy of Child & Adolescent Psychiatry, 32*(5), 990-994. doi: 10.1097/00004583-199309000-00016

Streissguth, A. E., & Kanter, J. E. (1997). *The challenge of Fetal Alcohol Syndrome: Overcoming secondary disabilities.* Paper presented at " Overcoming and Preventing Secondary Disabilities in Fetal Alcohol Syndrome and Fetal Alcohol Effects", September 1996, University of Washington Health Sciences/Medical Center, Seattle, WA.

Streissguth, A. P. (1997). *Fetal alcohol syndrome: A guide for families and communities.* Toronto, Canada: Paul. H. Brookes.

Streissguth, A. P., & Giunta, C. T. (1988). Mental health and health needs of infants and preschool children with fetal alcohol syndrome. *International Journal of Family Psychiatry, 9*(1), 29-47.

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics, 25*(4), 228-238. doi: 10.1097/00004703-200408000-00002

Streissguth, A., Barr, H. M., Kogan, J., & Bookstein, F. L. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE): Final report to the Centers for Disease Control and Prevention.* (Report No. 96-06). Seattle, WA: University of Washington, Fetal Alcohol and Drug Unit.

Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1997). Primary and secondary disabilities in Fetal Alcohol Syndrome. In A. Streissguth, & J. Kanter, (Eds.). *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities* (pp. 25-39). Seattle, WA: University of Washington Press.

Strongest Families (2012). Removing the barriers to care. Retrieved from http://strongestfamilies.com/

Swart, S. (2012). *Intertwining to fit in: A grounded theory study of caregivers with school-aged children with FASD.* (Unpublished doctoral dissertation). University of British Columbia, Vancouver, British Columbia, Canada.

Timler, G. R., Olswang, L., B., & Coggins, T., E. (2005). "Do I know what I need to do?" A social communication intervention for children with complex clinical profiles. *Language, Speech & Hearing Services in Schools, 36*(1), 73-85. doi: http://dx.doi.org/10.1044/0161-1461(2005/007

Triple P. (2013). Small changes, big difference. Retrieved from http://www.triplep.net/glo-en/the-triple-p-system-at-work/evidence-based/key-research-findings/

Waldrop, A. E., Santa Ana, E. J., Saladin, M. E., McRae, A. L., & Brady, K. T. (2007). Differences in early onset alcohol use and heavy drinking among persons with childhood and adulthood trauma. *American Journal on Addictions, 16*(6), 439-442. doi: http://dx.doi.org/10.1080/10550490701643484

Watson, S. L., Hayes, S. A., Coons, K. D., & Radford-Paz, E. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. part II: A qualitative comparison of parenting stress. *Journal of Intellectual & Developmental Disability, 38*(2), 105-113. doi: http://dx.doi.org/10.3109/13668250.2013.788137

White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York, NY: Norton.

Whitehurst, T. (2012). Raising a child with foetal alcohol syndrome: Hearing the parent voice. *British Journal of Learning Disabilities, 40*(3), 187-193. doi: 10.1111/j.1468-3156.2011.00692.x

Widom, C. S., & Hiller-Sturmhöfel, S. (2001). Alcohol abuse as a risk factor for and consequence of child abuse. *Alcohol Research & Health, 25*(1), 52-57.

Widom, C. S., Ireland, T., & Glynn, P. J. (1995). Alcohol abuse in abused and neglected children followed-up: are they at increased risk? *Journal of Studies on Alcohol and Drugs, 56*(2), 207.

Wilsnack, S. C., Vogeltanz, N. D., Klassen, A. D., & Harris, T. R. (1997). Childhood sexual abuse and women's substance abuse: National survey findings. *Journal of Studies on Alcohol and Drugs, 58*(3), 264.

Winslade, J. M., & Monk, G. D. (2007). *Narrative counseling in schools: Powerful & brief* (2nd ed.). Thousand Oaks, CA: Corwin Press.

Worcester, J. A., Nesman, T. M., Mendez, L. M. R., & Keller, H. R. (2008). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74*(4), 509-525.

Zabotka, J. M. (2013). *'How could I have done this?': A qualitative study of birth mothers who have children diagnosed with fetal alcohol syndrome* (Doctoral dissertation). Available from ProQuest Dissertation and Theses database. (UMI No. 1080532392)

Appendix A

FASD Diagnostic Criteria (Based on Chudley et al., 2005)

Fetal alcohol syndrome (FAS)

1. FAS with confirmed maternal alcohol exposure*

A. Confirmed maternal alcohol exposure*

B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the
premaxillary zone (e.g., flat upper lip, flattened philtrum and flat midface)

C. Evidence of growth retardation, as in at least one of the following:
- low birth weight for gestational age
- decelerating weight over time not due to nutrition
- disproportional low weight-to-height ratio

D. Evidence of central nervous system neurodevelopmental abnormalities, as in at least one of the following:
- decreased cranial size at birth
- structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurologic hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait,
poor eye-hand coordination

2. FAS without confirmed maternal alcohol exposure

B, C, and D as above

3. Partial FAS with confirmed maternal alcohol exposure

A. Confirmed maternal alcohol exposure*

B. Evidence of some components of the pattern of characteristic facial anomalies
Either C or D or E

C. Evidence of growth retardation, as in at least one of the following:
- low birth weight for gestational age
- decelerating weight over time not due to nutrition
- disproportionally low weight-to-height ratio

D. Evidence of CNS neurodevelopmental abnormalities, e.g.,
- decreased cranial size at birth

- structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurologic hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait,
poor eye–hand coordination

E. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone: e.g., learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention or judgment.

Alcohol-related effects

Clinical conditions in which there is a history of maternal alcohol exposure,*† and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are 2 categories, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered.

4. Alcohol-related birth defects (ARBD)

Congenital anomalies, including malformations and dysplasias

Cardiac
Atrial septal defects
Ventricular septal defects
Aberrant great vessels
Tetralogy of Fallot

Skeletal
Hypoplastic nails
Shortened fifth digits
Radioulnar synostosis
Flexion contractures
Camptodactyly
Clinodactyly
Pectus excavatum and carinatum
Klippel-Feil syndrome
Hemivertebrae
Scoliosis

Renal
Aplastic, dysplastic, hypoplastic kidneys
Horseshoe kidneys
Ureteral duplications
Hydronephrosis

Ocular
Strabismus
Retinal vascular anomalies
Refractive problems secondary to small globes

Auditory
Conductive hearing loss
Neurosensory hearing loss

Other
Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to alcohol teratogenesis remains uncertain.

5. Alcohol-related neurodevelopmental disorder (ARND)
Presence of A or B or both.

A. Evidence of CNS neurodevelopmental abnormalities, as in any one of the following:
- decreased cranial size at birth
- structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurologic hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

B. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone; e.g., learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention or judgment.

Appendix B

Appendix Semi-Structured Interview Guide 1

Parents will be asked to identify the child they are thinking about, and talk about during the interview.

Daily challenges

1. How do you approach parenting (child's name)?
2. What are some of the daily challenges of parenting (child's name)?
3. Can you give me an instance of a challenge you're talking about? What happened?
    a. What feelings came up for you in terms of parenting (child's name) in this instance?
    b. What thoughts came up for you in terms of parenting (child's name) in this instance?
    c. How did you respond when parenting (child's name) in this instance?
    d. What is something positive about the way you responded?
    e. Are there aspects of how you responded to (child's name) that you would like to have change? If so what are they?
    f. What was the overall result of this incident (e.g. for the child, family, self)
    g. What meaning did you take from this specific instance of a daily challenge that you experienced with (child's name)?

Note: Question 3 parts a to g will be asked repeatedly to explore as many specific instances as the parent can provide.

4. What lessons or insights do you feel people need to be made aware of in terms of parenting a child like (child's name)?
5. Is there anything else you would like to tell me?

Note: Follow up prompts will be asked throughout the interview to illuminate a deeper understanding of the participant's insights and experiences.

Appendix C

Semi-Structured Interview Guide 2

Daily challenges

1. How well do these preliminary themes and interpretations capture your experiences?
2. Is there anything else you would like to add or change?

Note: Prompts will be asked throughout the interview to illuminate a deeper understanding of the participant's insights and experiences that they shared in interviews and the journals.

Appendix D: Consent Form for Parents of Children on Waitlist for Assessment

University Northern of
British Columbia
3333 University Way
Prince George, BC, V2N
4Z9

Consent for Parents of Children on Waitlist for Assessment

Researchers:

Stephen Bennett	UNBC Counselling Program	e-mail bennet0@unbc.ca phone (250)960-6061
Dr. Corinne Koehn	UNBC Counselling Program	phone (250)960-6264
Dr. Cindy Hardy	UNBC Department of Psychology	phone (250)960-5814

Project title: Daily experiences of parenting a child on waitlist for assessment at NHAN and the applicability of a psycho-educational group

Purpose of Research:

We want to know about:

A) What types of challenges do parents of children on waitlist for assessment of suspected but not yet diagnosed FASD face on a daily basis and how do parents experience those challenges?
B) How can a support/psycho-educational group support the parenting of these children?

How the study works:

You are invited to be in the study because your child is on the waitlist for an assessment with NHAN. Interviews will take place at the Community Care Center or another location that is agreed upon by both the researcher and the participant. Each interview will take about one to two hours. There will also be time after the interview is over to talk about the interview process with the recorder turned off. I want to interview you before group starts. I want to interview you again after the group ends. In the first interview I will collect your demographic information and ask you questions about being a parent. In the second interview I will ask you to check my understanding of the information you gave me in the first interview. I will ask you some questions about your journal if you choose to complete the journal.. We will record your answers with a digital recorder. Someone will type out your spoken responses. This person will sign a confidentiality oath.. We will ask you to complete an optional journal at least once a week. The journal will ask you to respond to a set of questions about parenting and ask you about the group. You can complete the journal on-line or using a paper copy. If you complete the journal online you will have the option of typing your responses or recording your spoken responses. Once all of the information from the study has been examined you will be asked to help check the information. This process will involve responding by e-mail which should take between 30 and 60 minutes. You will have the chance to explain or add to the information, and let the researcher know if the findings "make sense". If you would prefer not to use e-mail, a telephone interview can be set up and a copy of the findings will be mailed to you. As a thank you you will receive a $20 grocery store gift card after completing each interview and an additional $10 gift card if you choose to complete the journal at least once.

Please check each box if you can read and understand the information.

Keeping your information private:

☐ All of the information we get will be kept in Dr. Hardy's lab in a locked cabinet in a locked room. Only the researcher (Stephen Bennett) and transcribers will have a key for the cabinet in which the information is stored. All of the computer files will be password protected.

☐ We will keep the names of everyone in the study private. People who read the report will not see your name or other identifying information anywhere.

☐ We may use some of what you say in your own words in our report. We will not use your name.

☐ We cannot keep information private if it is about harming yourself, harm to others, or abuse/neglect involving a child. We must take steps to protect people. If you tell us a child is in danger we will take steps to protect the child. If you tell us you want to hurt yourself or someone else we will take steps to protect everyone. Protecting you and your children may require us to give your name and other private information to police, social workers, or health care professionals so you can get the help you need.

☐ We cannot keep information private if there is a court order requiring us to share information. This is unlikely unless you are involved in a divorce or child custody hearings.

☐ You will be asked to make up a fake name which will be used when mentioning some of what you say in your own words in our report, publications, presentations or thesis.

Asking questions:

☐ If you have any questions you can e-mail or call Stephen. His e-mail and phone number are at the top of this letter.

☐ Any concerns about the research can be mentioned to the Office of Research, UNBC at (250) 960-6735 or reb@unbc.ca

☐ You can get a summary of the research by contacting the researcher Stephen Bennett at bennet0@unbc.ca. A summary of the results will be sent to you. The summary should be available by March 2015.

☐ Please send me a summary of the research using the following address.

____

____

_____

Possible Risks:

☐ You might feel uncomfortable answering some of the questions. You do not have to answer the questions if you do not want to. You can skip any questions you do not want to answer.

Possible benefits:

☐ The information will help people understand what it's like to parent a child on the waitlist for assessment.

☐ The information will help make the next group better.

☐ The information may help in the creation of services for parents and families.

What we will do with your information:

☐ We will use your answers to give conference presentations, write a thesis and publications. We will not use your name in the documents. It is unlikely that it will be possible to identify you from the report.

☐ We will ask you for permission to have Dr. Hardy give us some of your information from the group. We will ask for your answers on the questionnaires (Parenting Sense of Competence Scale & Parent Behaviour Inventory).

☐ The researcher's supervisor Dr. Koehn will check his analysis and spot check interview materials to ensure they are accurate.

☐ Dr. Hardy and the Learning Together team will not see any of your comments until after your group has finished.

☐ The presentations, thesis and publications will tell people what worked well for group. The report will also tell people what could be changed about the group.

☐ The presentations, thesis and publications will tell people what it's like to be a parent of a child on the waitlist for assessment.

☐ If you want a copy of the report you can e-mail or call Stephen and he will give you a copy. Stephen's e-mail and phone number are at the top of the first page.

☐ After the project is done we will keep information that identifies you only for one year.

☐ After the project is done we will keep information that cannot be linked to you (e.g., a written copy of what you said) for seven years. At the end of the seven years we will destroy all of your information. Paper information will be shredded and computer files will be deleted.

Consent

☐ It is your choice to be in this study. You can stop being in the study at any time. If you stop, things will not change with the group. You can stay in the group even if you are not in this study. If you withdraw from the study, you can keep any gift cards you have received so far.

☐ You can stop taking part in the study at any time. If you decide to stop, you have the choice of allowing us to keep the information you have provided or having the information destroyed.

☐ You can ask questions at any time.

You have three choices. Please pick one of these three choices.

- ☐ I want to be in the full study including two interviews and weekly journal.
- ☐ I want to be in the study to do two interviews but not the weekly journal.
- ☐ I do not want to be in the study.

Put your name below only if you agree to be in the study.

Sign your name here Date Print your name here

Name of support person Phone number
(If you wish to involve a support person)

Researcher name Date

Appendix E

Demographic Information

Code:____________ (filled in by researcher)

Please complete the following:

1. Current age: _____
2. Gender ______________
3. Highest education level completed:
    a. Grade school
    b. Grade 12
    c. Some college or university
    d. College diploma
    e. University undergraduate degree
    f. University graduate degree
    g. Other (please specify) _______________
4. Marital Status
    a. Married
    b. Separated
    c. Divorced
    d. Common law
    e. Never Married
    f. Widowed
5. What is your ethnic origin (e.g., Caucasian, Asian, Aboriginal etc.)?

    ____
6. Current employment status:
    a. Employed full time
    b. Employed part time
    c. Employed seasonally
    d. Unemployed
    e. Permanently out of labour force due to illness/disability
    f. Out of labour force due to decision to be a stay at home parent
    g. Student
    h. Other (please specify) _________________
7. Type of occupation: (please specify, e.g., stay at home parent, sales clerk, manager, mechanic, teacher) ____

8. What is the name of your child who is being assessed for FASD?

   ____

9. How old is (child's name)? ____

10. What is your relationship to (child's name)?
    a. Biological parent
    b. Step parent
    c. Foster parent
    d. Adoptive parent
    e. Other (please specify) ______________________________

11. If parent is not birth parent, ask: How long have you parented (child's name)?__________________________

Appendix F

Journal Questions

Note: These questions relate to parenting your child who is suspected to have FASD
Daily challenges

1. Please describe a parenting challenge that happened this week.
    a. How long ago did this challenge take place?
    b. What feelings came up during the challenge?
    c. What thoughts came up during the challenge?
    d. How did you respond to the challenge?
    e. What meaning does this experience have for you?
    f. What other skills, if any, would you have liked to use with this particular challenge?
    g. If you were unable to use a skill with this challenge, what prevented you from using the skill?
    h. What was the outcome of this challenge for the child?
    i. What was the outcome of this challenge for the family?
    j. What was the outcome of this challenge for you?

2. How do your parenting experiences this week compare to the previous week?

Group Feedback

3. What did you find most effective about the group this week?

4. What could be added/changed to enhance the group this week?

5. Which skills/knowledge learned in the group did you use the most this week?

Appendix G

Transcriber Oath of Confidentiality

As the transcriptionist hired to transcribe interviews and journal entries for the research thesis, Daily experiences of parenting a child with suspected FASD and the applicability of a psycho-educational group, I will treat as confidential all information learned through transcribing the interviews and journals of research participants.

To help ensure the safety and confidentiality of data, transcriptions will be password protected. I will not print any hard copies. When transcriptions are complete, I will electronically send them to the researcher using only my UNBC email account. I will delete the files from my hard drive and sent mail once the researcher indicates that the files have been successfully received.

I further understand and agree that this oath of confidentiality will continue in force indefinitely, even after I cease being a volunteer on this thesis research.

I also agree to indicate if I know a family taking part in the study before I transcribe their information. If I know a family I will ask you to assign another transcriptionist to work with that family's information.

Name of Transcriptionist: (print): ____
(signature): ____
Date: ____________________

Researcher's Name: (print):
____
(signature):
____

Date: _______________________

Project Contact Information
Stephen Bennett, UNBC bennet0@unbc.ca

Appendix H

Composite Analysis of the Data

All Participants Summary

Please read the following summary and see how well it captures the daily challenges and your experiences of parenting. Not all parts of the summary will apply to you. However, you should see your experiences reflected in parts of the summary.

Challenging Environments

All parents talked about having to deal with at least one type of challenging environment. The type of environment varied. However all the environments involved parents interacting with other people or organizations such as the health authority in an effort to parent their child as effectively as possible.

Insufficient Supports For the Child

Parents explained that they were faced with insufficient supports (e.g., information from professionals). Parents expressed anger, frustration, anxiety, fear, and fatigue as they sought to find adequate supports. There was a sense of regret and sadness over the challenges their child could have avoided if supports had been available. For example, parents talked about how their child could have avoided struggles in school if proper educational supports (e.g., adapted assignments) had been present. Not having the same support network as other families brought up feelings of sadness and a sense of loss. Parents focused on continuously advocating for what their child needed, identifying what kind of services the child needed, providing informal supports in the home, (e.g., working on math with the child) and doing research to come up with new ideas about how to help the child. In addition, parents sought out support from friends and family to help cope with the stress of insufficient supports. Parents explained the need to accept that even getting the supports (e.g., assessment) would not solve all the problems. It was important to always seek to reduce both uncertainty and unanswered questions. However other parents explained the need to make sure they didn't expect a single universal solution. Some parents mentioned that they were considering moving to a new location that would have more supports. It was also important to find time in the day to talk with the child to see how the day was going as a way to help compensate for missing supports. These talks allowed parents to identify challenges their child was facing and offer support and encouragement that would not otherwise be provided. As parents made progress towards getting more support for their child they expressed feelings of accomplishment, validation and pride. Parents talked about being frustrated by the lack of supports and resources available to their child before they received a formal FASD assessment.

Parents Not Feeling Heard by Professionals

Parents didn't always feel heard and understood by professionals. Some parents felt angry; other parents talked about having to cope with the fear that professionals would place the child with another caregiver. Parents talked about how these fears sometimes led to expecting the worst. Parents reminded themselves that they were doing a good job of parenting the child. In other cases, parents spoke of being frustrated because professionals didn't understand what it was like to parent a child with suspected FASD. The expectations placed on parents by professionals were, in parents' opinion, unrealistic. Parents talked about spending a great deal of time trying to get professionals to understand what their child needed and reassuring the child that eventually supports would be in place. Some parents expressed intense frustration and disbelief at the opportunities that had been lost because adequate supports were not initiated by professionals. Despite the ongoing struggle to secure supports parents commented on the steps that had been taken to develop individualized supports for their child and that there had been some successes.

Multiple Adults Raising the Child

Parents faced challenges related to their interactions with other people (e.g., foster parents, biological parents etc.) who are helping to raise the child. Foster parents spoke about wanting to have the biological parent involved in the child's life. However, foster parents experienced fear, disbelief and frustration because in their opinion the biological parent frequently could not look after the child without supervision. Some foster parents also talked about feeling betrayed and angry towards the biological parent because the biological parent's actions created problems related to setting up supports and resources for the child. Moreover, foster parents expressed sadness and a sense of loss for the child because the biological parent was not more involved in the child's daily life. Foster parents worked towards trying to have biological parents more involved by anticipating when problems might arise and coming up with creative solutions such as having the biological parent spend time with the child at the foster parent's home. The child would sometimes become distressed by the absence of the biological parents so foster parents made an effort to be honest with the child when answering questions, helped the child calm down, always focused on being patient with child, reassured the child, and focused on the positive things that were going on in the child's life. Foster parents also decided which things were most important and focused on those first, accepting that other less important tasks might not get addressed immediately. Despite feeling fatigued, foster parents expressed feelings of accomplishment as they found ways to integrate the biological parent into the child's life. These successes gave foster parents a sense of hope that progress was possible. None of the biological parents commented on their experiences of interacting with foster parents.

Regulating Video Games

Other parents found themselves having to regulate their child's use of video games. Some parents regretted giving their child access to video games because the child would copy the aggressive and disrespectful behaviour used in the game. Parents resorted to using methods that they identified as not very effective, such as yelling. This type of approach did not work because the child became angry and it became very difficult to communicate with the child. As an alternative parents started anticipating which games the child should not play (e.g., Grand Theft Auto) and being consistent with rules around which other games could be played. Parents also took time to explain the rules to the child and helped promote informed choices by making the child aware of what the consequences were for breaking the rules. Moreover, parents found games that fostered cooperation or skills such as math. These skills based games actually helped improve the child's behaviour and comprehension. Other parents found video games beneficial because they allowed their child to interact with their friends in a collaborative way (e.g., Minecraft). Parents found video games to be at least partially beneficial as long as their use was tailored to meet their child's needs. For example, parents would pick games that targeted academic skills that needed to be improved. Being able to transform a challenge into a potential solution gave parents a sense of validation and pride

Social Isolation and Consequences of Bullying

Parents explained that they worried their child would become socially isolated as peers matured. This concern was particularly important as parents thought about their child eventually going to high school. Parents experienced fear and frustration at the prospect of their child becoming socially isolated. Parents spent time anticipating what might lead to this isolation (e.g., impaired social skills) and sought to prioritise teaching their child skills essential to increased independence and maturity. Furthermore, parents spent time explaining skills and reassuring their child that progress and improvement were possible. As with other skills, parents felt a sense of pride when their child started to acquire a new skill that would reduce the chances of social isolation. Some parents talked about how their child was already experiencing social isolation and bullying. Parents felt angry and betrayed that other adults had not stepped in to help prevent the social isolation and bullying. Parents spent time letting the child talk about being bullied in a safe environment and helped the child regulate emotions. Parents also advocated for their child and tried to put supports in place that would stop the bullying. Parents explained that they were committed to helping their child through the bullying but always being exposed to the child's anger and frustration was exhausting and overwhelming at times.

Setbacks Related to Social Interactions

Parents also explained that their child experienced setbacks related to social situations such as interactions with peers and teachers. Parents felt angry and at times fatigued in response to such setbacks. Some parents made a point of deciding which issues were most important and which ones could be dealt with at a later date. Other parents experienced fear and anxiety over how their child would interact with peers. A major concern was that the child would become a follower and be manipulated by other children. Parents talked about how they felt betrayed and let down by staff who failed to adapt school work so that the child could learn. The feeling of being let down was increased by the fact that parents took time to explain their child's needs and advocate for accommodations in advance. However, parents felt their concerns and the information they provided were not used by teachers. Parents often broke tasks, such as homework, down into steps to make them more manageable. Parents also found creative ways to mediate the setbacks their child was facing (e.g., getting a private tutor). Moreover, parents focused on making sure that their child would be able to make life choices. Avoiding setbacks in social settings, such as school, was vital because parents did not want to unnecessarily limit their child's opportunities later in life. Eventually, parents want to see their child have the confidence and skills to stand up and advocate for what they want to do with their life. Parents talked about spending time explaining and teaching the child skills that they had not previously learned. Parents explained that in some cases the child simply had not had the chance to learn a particular skill. Seeing the child learn a new skill or make new supportive friends gave parents a sense of success and progress. These accomplishments made it easier for parents to deal with the ongoing uncertainty of how the child would handle social settings as they matured.

Child's Impaired Cognitive Functioning

All parents were helping their child cope with the impact of a cognitive deficit. These challenges ranged from children not being able to understand concepts like math to an inability to know when a situation is unsafe.

Child's Anger Related to Having a Cognitive Deficit

Parents talked about how their child knew about the cognitive difficulty created by suspected FASD. The child was often angered by the challenges and limitations that existed. Parents explained the need to determine which issues could be addressed and which issues were beyond their control. For example, parents could help their child cope with the inability to fully comprehend the absence of a biological parent but could not always reunite the child with the biological parent as often as the child wanted. Parents also described feeling depressed and anxious as they watched their child come to terms with having cognitive impairments. Parents were angry and frustrated that they could not always help their child overcome challenges, such as understanding math. Parents used several skills to help mediate their child's anger, such as being honest when they didn't have the information the child wanted, consistently helping the child try and find ways around challenges and explaining things in a different way when the child didn't understand and became angry. Parents commented on the importance of helping the child understand the consequences of their actions since the child often became angry when the reasons for consequences were unclear. However, it was important for parents to find moments when the child was starting to calm down. Proper timing of information helped reduce the child's anger. Waiting for the right moment also meant that parents needed to be patient and often let the child vent their anger before a conversation could happen. Some parents expressed fear over how they would manage when the child was a teenager and became angry. The concern was that eventually the child would be stronger than the parent and someone could be hurt when the child was angry. Other parents commented that it was important to model for the child, through pictures and demonstrations, how a person who is angry should act. Some parents would actively remove something from the environment that was making the child angry such as homework. The child was reassured that once the anger had passed the removed item would be returned. Parents actively sought resources and supports, such as educational groups, that could help manage and reduce their child's anger. Parents talked about how being consistent with rules and expectations had helped reduce their child's anger. These accomplishments gave parents a sense of relief and accomplishment. However, some parents expressed feelings of dread and fatigue as they faced the challenge of managing their child's anger later in life. Specifically, parents worried about their child's anger in relation to high school and the increasing academic demands.

Child Not Understanding Information

A cognitive impairment all parents faced was their child not understanding information such as spoken instructions or written information. Some parents talked about feeling anxious and angry when their child could not understand something because the lack of comprehension made it hard to help the child. Other parents had a sense of fascination and disbelief related to the fact that the child understood some information well but completely missed other instructions. Parents had a strong desire to figure out how their child interpreted and remembered information. Parents focused on making sure their child understood information so that eventually the child would be able to make their own choices and decide what to do with their life. To help facilitate this freedom of choice some parents focused on deciding which skills the child will need to know in the future, such as how to count money, and which skills are less important for the child's future, such as knowing how to use the Pythagorean Theorem. Many parents broke tasks down into steps, explained things repeatedly in different ways, and made sure the child had time to talk with the parent each day. Foster parents described that sometimes the child did not understand how to do a task simply because it had never been properly described or demonstrated before. Other parents found that they had to give information in small chunks and then give the child time to process what had been said before providing the next piece of information. Other useful skills included having the child repeat verbal information, writing instructions down in a list, using simple words when talking to the child and changing the expectations placed on the child when needed. Parents commented that it was important to check the child's comprehension because sometimes the child would give the impression that the information had been understood when in fact the child was just trying to end the conversation. The fact that every child understood information differently left parents feeling exhausted at times. The task of finding the unique solution for each child could be daunting and different strategies were often needed for different kinds of information such as spoken or written instructions. Other parents spoke about how they wanted to change the strategies that had been used in the past because these approaches had not worked well. Parents talked about how they were able to increase their child's understanding somewhat, even without enough formal supports, and this gave parents a sense of relief and success. However, some parents remained protective of the child and often worried about a negative outcome if the child's comprehension would not improve considerably. For example, some parents talked about the possibility that the child could be placed with another caregiver. The fear was that the professionals would recommend another caregiver, presumably with more resources and energy, as a way to facilitate the child's cognitive development.

Child Finding Change Difficult

Other parents explained that their child found changes to routine hard to accept. Parents felt anxious and fearful when their child needed to adjust to a change. The need to constantly anticipate and mediate changes was frustrating at times for parents. For some parents this frustration turned into feeling fatigued. Some parents used skills such as being honest with the child about the drawbacks to change, making the child aware of how change can be positive, introducing changes in gradual steps, allowing the child to make some choices around how change was handled, and being mindful of when the child was finding the change especially hard. Parents emphasized that there was a need to be patient with the child and allow them to accept the change gradually. Other parents used skills such as encouraging their child to keep trying new things as a way to make change easier. When the child felt uneasy about change, parents helped by offering frequent reassurance and encouragement. Parents were comforted by the realization that with persistence the child usually embraced the change. Parents expressed a sense of relief and accomplishment once the child was familiar and comfortable with the change.

Child's Not Understanding When a Situation is Unsafe

Some parents experienced intense fear around their child's inability to determine when a situation was unsafe. Parents focused on anticipating risks, such as harmful objects, so that these items could be removed from the environment. Parents also had honest discussions with the child about the need to be cautious around people they don't know and the importance of following rules, such as not leaving the yard, alone. Parents also used concrete demonstrations that included drawing a line on the ground to show the child the boundaries of their play area. In addition, parents sought support from trusted people to help supervise the children. Parents were often hyper vigilant and expressed confusion over their child's inability to tell when a situation was unsafe. Parents coped by reminding themselves that there was only so much anyone could do to protect their child and some degree of uncertainty and risk was unavoidable. After taking every reasonable precaution some parents found comfort in their religious beliefs and felt that God would help keep their child safe. Moreover, parents struggled with finding a balance between giving more independence when the child was ready and still keeping the child safe. Parents explained that the constant challenge of keeping the child safe was complicated by the uncertainty of how this challenge would change as the child matured.

Child's Other Medical Conditions

Parents talked about their child likely having other medical conditions in addition to the suspected FASD. Parents talked about feeling angry, fearful, and anxious as they dealt with their child's suspected additional medical conditions. Parents spent time meeting with medical professionals in an effort to determine what other conditions their child had. However, as noted above, parents didn't feel that professionals understood their concerns and that there were insufficient supports for their child. Some parents felt depressed and were in disbelief as they tried to help their child cope with undiagnosed conditions. Other parents feared that the undiagnosed medical conditions could cause permanent damage to their child's physical health. In some cases the undiagnosed medical conditions such as hypersensitivity were compounded by the suspected FASD. The child did not understand and/or remember to eat regular meals and the hunger aggravated their hypersensitivity. Parents felt overwhelmed, at times, having to deal with multiple concurrent medical conditions. Despite feeling overwhelmed at times parents described the need to be patient when interacting with their child. Parents used several strategies such as, doing research to come up with potential solutions, getting support from friends and family members, and setting up a schedule for essential tasks, for example eating. Through trial and error parents found ways to manage some of the other medical conditions which gave them a sense of hope that progress was possible. Parents sometimes felt it was not possible to manage their child's medical conditions; at these times there were feelings of hopelessness, dread, and a need to give up. However, parents' love for their child made it easier for them to persevere.

Seeking to Facilitate the Child's Independence

All parents identified challenges that needed to be resolved so their child could be independent. Some of these challenges were situational such as teaching the child how to do laundry. Other challenges related to how the child's emotions impacted the ability to respond to situations.

Facilitating Problem Solving and Taking Responsibility

All parents wanted to help their child solve problems independently and take responsibility for their actions. Parents expressed feeling angry, frustrated and fearful when their child found independent problem solving difficult. These emotions were related to parents' concerns that the child would not be able to live independently and parents worried who would care for the child later in life. Other parents also talked about feeling depressed over the realization that their child may never be able to live independently. Parents focused on deciding which skills, such as doing laundry on their own, were most important for the child to achieve independence. Parents felt fatigued by the task of helping the child to become independent so it was vital to decide which skills needed the most attention. Many parents found that breaking tasks down into step by step instructions and repeatedly showing the child how to do each step was very helpful. Sometimes the child would become discouraged when a task seemed too hard. Parents reassured the child and explained that the child only had to be willing to try. If the task wasn't done successfully there would always be a chance to try again. Importantly, some parents explained that taking responsibility also meant that their child would eventually make their own, informed, life choices rather than just simply being able to solve problems, including dirty laundry, on their own. Some parents talked about having to simplify their expectations and re-teach foundation skills (e.g., basic math) which the parents thought the child had already learned. Other parents got help from neighbours who agreed to act as an emergency contact so that the child could practice steps towards independence, such as being home alone. Having these supports made it much easier for parents to simulate independence for the child while still maintaining the child's safety. A few parents talked about the need to remove barriers to independence by reminding the child that with each new day past disagreements or failures no longer existed and the child could confront the day with a fresh start. It was important to keep the child focused on successes so that they didn't become discouraged. All parents spoke about steps their child had taken towards independence and these accomplishments validated parents' ongoing efforts and commitment to support their child.

Reducing the Child's Dependence on the Parent

Some parents dealt with trying to ensure that their child did not become overly dependent on them for support. Parents worried that because challenges could be discouraging the child would not become as independent as possible. Parents expressed anger over the fact that their child would sometimes assume a task was too difficult without even trying and look to the parent to always explain what needed to be done. Parents talked about needing to remind themselves that they were not always responsible for the child's mistakes and sometimes the child had to experience consequences as a learning tool. Finding time to talk with the child and explain why consequences occurred were very important so that the child would start to understand how actions impact outcomes, such as having to get up early to put clothes in the dryer so there would be dry clothes for school. Some parents tried to reduce their child's dependence on adults by showing the child all the fun opportunities that would come with increased independence. Other times parents changed the environment. For example, parents bought foods that were easier for the child to prepare on their own. Parents with older children were relieved when signs of increased independence appeared. Some parents with very young children felt extremely protective and talked about trying to not create unnecessary dependence. Having a child with suspected FASD was unique because parents found themselves not always insisting that a child learn a skill or complete a task. Parents described that right now it was hard to start building independence because of the child's age and undiagnosed FASD. Parents also realized that there was a need to ensure that expectations were gradually increased over time so that the child would be able to develop independence.

Helping the Child Self-Regulate

Another challenge related to fostering the child's independence was helping the child learn to self-regulate their emotions and behaviour. Parents were particularly concerned and angry about their child's lack of self-regulation because the child had to be calm before other challenges, such as lack of understanding, could be addressed. Parents talked about being fearful when they thought about their child getting into trouble with peers because of poor self-regulation. In some cases, the reason for the child's poor self-soothing was unknown which left parents feeling frustrated because there was often no way of helping the child calm down. In these instances parents talked about the need to accept the absence of an apparent cause. Parents also had friends and family with whom they could talk as a way to express their frustration at not being able to offer more help to their child. Helpful parenting skills included picking up on cues that the child was escalating and then helping the child calm down, finding times when the child was able to practice self-soothing techniques and, when possible, removing triggers from the environment. Although parents identified ways in which their child's self-regulation had improved there was an ever present concern that the progress was temporary. Some parents were caught between feeling validated by the progress and fearful of progress being lost.

Confrontational Attitude

At times parents had to help their child communicate in was that did not include physical or verbal aggression. However, this challenge made the use of parenting skills harder since the child needed to be calm for many of the skills to be effective.

Experiencing Child's Verbal Disrespect

Parents sometimes found themselves dealing with a verbally disrespectful child. Some parents had a sense of dread, fatigue and being overwhelmed when their child was disrespectful. Similar to the lack of self-regulation the child being verbally disrespectful made it extremely difficult to work on other challenges. Some parents became angry which intensified the child's behaviour. Parents described that they preferred to use strategies such as removing video games for a set period of time, knowing when to give the child some alone time to calm down, helping the child understand how hurtful their words were and explaining consequences after the child had stopped being disrespectful. Some parents commented that times when the child was disrespectful were useful in that there was an opportunity to have the child practice self-regulation. Other parents talked about wanting to learn new strategies so that there would be no need to use methods that parents found ineffective. The ineffective strategies only made the child more angry and disrespectful. Parents were disappointed that more resources and supports were not available. Parents commented that being consistent with rules and expectations could be exhausting. However, consistency reduced the instances of the child being disrespectful.

Dealing With Child's Physical Aggression

Other parents found that their child could be physically aggressive (e.g., hitting). Parents commented that they were anxious and at times fearful. Feelings of anxiety were related to not being able to understand why the child became aggressive. In the absence of a potential cause, parents were often unsure of how to help correct the behaviour. Feelings of fear stemmed from the unpredictable nature of the aggression and parents worried how they would respond when the child was older and stronger. Some parents expressed regret that the only solution they had found so far had been to restrain the child. Parents were eager to learn new, nonphysical ways to mediate the child's use of violence. Parents explained that there was a need to try and anticipate what might trigger an outburst while also accepting that an explanation may not emerge. After the child had calmed down, parents repeatedly spent time explaining why the child's actions were not acceptable and trying to help the child find other ways of coping with being angry or upset. Some parents also noted that they tried to teach the child to engage, without reminders, in using self-control.

Meta Themes

There were several themes that were present in all parents' interviews and occurred across challenges. These themes were hope, parents' self-awareness, parents trying to understand their child's perspective, and parents' use of flexibility and creativity to address challenges.

Parents' Hope

Regardless of the challenge all parents felt a sense of hope and believed that progress was possible. Past successes and positive experiences gave parents a reservoir of determination. Confronting challenges and setbacks was made easier by parents' sense of hope and determination to work towards solutions. The enduring sense of hope offset feeling of weariness at times.

Parents' Frequent Self-Reflection

Parents spent a considerable amount of time reflecting on situations and challenges. It was useful to reflect on helpful and unhelpful parenting behaviours. Some parents realized that they did not have to assume responsibility for everything their child did which made it easier for them to let go of self-blame and unconstructive criticism. Other parents found self-reflection helpful but spoke of the need to remember that it was impossible to understand the reasons for every aspect of their child's behaviour. Finally, self-reflection and self-awareness allowed parents to know their limits. Knowing when to step back from a situation and take a break made it easier for parents to feel less fatigued and angry.

Understanding the Child's Perspective

In most situations parents made an effort to understand events from their child's perspective. Looking at situations from another point of view allowed parents to appreciate how difficult certain things, such as not being able to understand the world, must be for their child. This deeper understanding of their child's world often made it easier for parents to be patient. Furthermore looking at situations from the child's perspective often facilitated the development of new skills or solutions for challenges.

Parents' Flexibility and Creativity

Parents constantly demonstrated flexibility and a desire to find creative ways of helping their child. Moreover, this creative tendency seemed to almost always be present. Some parents even generated creative new solutions over the course of our interview. Their creativity and flexibility helped them cope with the fact that each child required a different solution. In addition, solutions that helped the child changed over time and from one situation to the next. All parents sought resources and supports that could help fuel their creativity.