A Multiple Case Study of Caregivers' Experiences of a Psychoeducational Support Group for Caregivers of Children with Fetal Alcohol Spectrum Disorders (FASD): An Embedded Mixed Methods Study

by

Katherine Mary Roger

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Department of Educational Psychology
University of Alberta

Abstract

Children with Fetal Alcohol Spectrum Disorders (FASD) can experience a number of neurocognitive deficits and associated adverse outcomes. Stable home life helps protect children with FASD against adverse outcomes; however, their primary caregivers typically have significantly higher levels of stress, which can affect the quality of caregiver-child interactions. Education and support groups have been found to be effective for decreasing stress and increasing feelings of competence for caregivers of children with disabilities. The primary aim of this embedded mixed methods case study was to explore the impact of a psychoeducational support group for three adoptive and kinship caregivers of a child diagnosed or suspected of having FASD. Quantitative data (i.e., questionnaires) was enhanced and augmented by qualitative data (i.e., interviews, observations, and feedback forms). Feelings of hope, changing perspectives, learning about disability-specific information, creating social connections, and opportunities to hear and share experiences were particularly helpful for caregivers. Stress was also a large factor for caregivers, and questionnaires indicated all caregivers were experiencing high levels of stress, both before and after the intervention. Despite reports that the group helped caregivers deal with stress, only interviews underscored these changes; thus, collecting both quantitative and qualitative information was helpful for understanding caregivers' experiences. Implications for practice based on these experiences include the benefits of a needs assessment for caregivers, the value of a knowledgeable facilitator, the importance of group cohesion and the inclusion of a range of caregivers, the necessity to remove barriers for attendance, and the need to provide access to additional services for caregivers. These findings will help inform recommendations for future education and support groups for caregivers of children with FASD.

Preface

This thesis is an original work by Katherine Roger. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “A multiple case study of caregivers’ experiences of a psychoeducational support group for caregivers of children with Fetal Alcohol Spectrum Disorders (FASD): An embedded mixed methods study”, No. 27316, January 23, 2012.

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CHAPTER ONE

Introduction

Overview of the Issue

The stress of raising a child with a disability has been the basis for extensive research and intervention over the past several decades (Baxter, Cummins, & Yiolitis, 2000; Saloviita, Italinna, & Leinonen, 2003). Despite higher levels of stress, there is great variability in levels of adaptation for families with children with disabilities (Singer, 2006). Multiple factors interact to influence how families will adapt to a stressor (McCubbin, Thompson, Pirner, & McCubbin, 1988; McCubbin & McCubbin, 1991). The Contextual Model of Family Stress (Boss, 2002), based on Hill's ABCX model (Hill, 1949), focused on three elements that interact to impact family adjustment: characteristics and experiences of raising a child with disabilities, appraisal of the situation, and the resources available to the family. These elements have been supported by research concerning families' experiences of raising a child with a disability (e.g., Frey, Greenberg, & Fewell, 1989; Hassall & Rose, 2005; Saloviita et al., 2003).

Being a caregiver[1] for a child with Fetal Alcohol Spectrum Disorders (FASD) comes with many additional challenges over and above the typical stressors of being a caregiver. Caregiving for a child with FASD requires additional time, energy, and consistency (Giunta & Streissguth, 1988). Children with FASD can experience a number of neurocognitive deficits, including in the areas of executive functioning, attention, memory, and social cognition (Kodituwakku, 2009). Prevalence rates of FASD in Canada are estimated to be nine cases per 1000 infants born (Chudley et al., 2005). There are tremendous societal and economic costs

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[1] The term *caregiver* has been used throughout this document instead of the term *parent*. Caregiver for a child can be defined as someone who attends to the needs of the child. It has been used to allow participants the opportunity to use their own terminology and to be more inclusive for a range of caregiving roles. Caregiving has previously been used in several studies in the area of FASD (e.g., Leenaars, Denys, Henneveld, & Rasmussen, 2012, Shepard, O'Neil, Down, & Morris, 2012)

associated adverse outcomes that occur as a result of these deficits. Individuals with FASD are at increased risk of disrupted school experience, inappropriate sexual behaviours, and trouble with the law (Streissguth, 2001; Streissguth et al., 2004). There is also a significantly increased risk for mental illness and addictions for individuals with FASD (Streissguth, 2001). Stable, nurturing homes help protect children with FASD against adverse outcomes; however, living in such homes is not typical for children with FASD (Olson, Oti, Gelo, & Beck, 2009). Supportive and stable homes consist of positive and consistent parenting practices with involved caregivers who provide basic needs for their children.

To date, most studies have focused on caregivers' experiences of raising children with FASD by studying caregivers' perspectives (e.g., Brown & Bednar, 2004; Gardner, 2000; Granitsas, 2004; McCarty, Waterman, Burge, & Edelstein, 1999). These studies revealed caregivers' challenges related to children's memory, comprehension, and behavioural difficulties (Gardner, 2000; Sanders, 2008) and their worries regarding their children's development and futures (Gardner, 2000). Caregivers have also experienced barriers when trying to access services (Granitsas, 2004; Sanders, 2008). Practitioners can play an important role as advocates and resources for caregivers and families (Granitsas, 2004; McCarty et al., 1999). Caregivers also indicated several needs, including the continuation of supportive services such as support groups and caregiver-mentor programs (Brown & Bednar, 2003; Brown, Sigvaldason, & Bednar, 2005; Huculak & McLennan, 2009; McCarty et al., 1999) as well as educational materials and resources (Brown & Bednar, 2003; Brown et al., 2005; Brown, Sigvaldason, & Bednar, 2007; McCarty et al., 1999). The current study investigated caregivers' experiences of a psychoeducational support group in order to further our understanding of their support and education needs.

Factors contributing to high levels of stress experienced by caregivers of children with FASD have been established. Many studies have demonstrated that also experience high levels of stress (e.g., McCarty et al., 1999; Paley, O'Connor, Kogan, & Findlay, 2005; Sanders, 2008). Several factors have been found to predict caregiver stress for caregivers of children with FASD. Paley and colleagues (2005) found children's externalizing, internalizing, executive functioning, and adaptive behaviours significantly predicted caregivers' stress. High levels of caregiver stress can negatively affect the quality of parent-child interactions, which is central for positive child development (e.g., Plant & Sanders, 2007). Caregiver stress has been found to link to important caregiver variables, including caregiver sense of competence, perceived knowledge, and support, all of which can positively affect caregiver-focused intervention outcomes (Pottie & Ingram, 2008; Pottie, Cohen, & Ingram, 2009; Singer, Ethridge, & Aldana, 2007), which may interact to influence families' quality of life. In particular, caregivers' sense of competence affects caregiver competent behaviours and positive parenting practices (Coleman & Karraker, 1998; Jones & Prinz, 2005). Research concerning caregiver sense of competence has demonstrated a consistent relationship between lower caregiver self-efficacy and higher reports of children's behaviour problems (Mash & Johnston, 1983). Coleman and Karraker (2003) also found that caregivers with higher caregiver sense of competence tended to perceive their children as less difficult. Caregiver education has been found to increase caregivers' levels of self-efficacy (e.g., Ialongo et al., 1999), which has also been found to positively affect caregivers' observed skills (Webster-Stratton, Reid, & Hammond, 2004). Finally, numerous studies have indicated the ameliorating effects of social support for decreasing caregiver stress (e.g., Baldwin, Brown, & Milan, 1995; Pottie & Ingram, 2008). Seeking social support has been indicated to be an effective coping strategy for caregivers of children with FASD (e.g., Gardner, 2000).

To help ameliorate risk factors and increase potential protective factors for children with FASD, it is important to investigate how to best help caregivers provide supportive home environments to children with FASD. In particular, caregiver group interventions, such as education and support groups, have been found to be a cost-effective way for helping support caregivers of children with disabilities (Barlow & Stewart-Brown, 2000; National Institute for Health and Clinical Excellence, 2006; Niccols, 2008). Education and support groups have been found to help decrease caregiver stress, increase caregivers' sense of competence, and increase caregiver knowledge, which promotes positive parenting and supportive home environments (Bailey, 2007; Bertrand, 2009; Bohjanen, Humphrey, & Ryan, 2009). However, little is known about the benefit of education and support groups for caregivers of children with FASD. Furthermore, little research has investigated the impact of education and support groups for caregivers of children with disabilities using mixed methodology, despite a call for an increase in mixed methods research in order to better understand child development, ecological family processes, family adaptation, stress, and positive functioning (Plano Clark, Huddleston-Casas, Churchill, Green, & Garrett, 2008; Turner & Johnson, 2010).

The Purpose of the Present Study

The purpose of this study was to explore caregivers' experiences of participating in a psychoeducational support group for caregivers of children with FASD. The psychoeducational support group was for adoptive or kinship caregivers of children with FASD and aimed to provide information and support through structured and open discussions. The study's main mixed methods research question was: What are caregivers' experiences of participating in the psychoeducational support group and how are these experiences related to caregivers' levels of stress, sense of competence, support, and quality of life? Three subsequent research questions were addressed: (a) To what extent are caregivers' level of stress, sense of competence, support, and quality of life affected by participating in the psychoeducational support group? (b) What are caregivers' individual experiences as a participant in the psychoeducational support group? In particular, what are the aspects of the psychoeducational support group that are reported by caregivers' to be benefits and barriers? (c) What are the similarities and differences of caregivers' experiences of participating in the psychoeducational support group when compared across individual case studies? Addressing these research questions will inform future education and support programming for caregivers of children with FASD.

Guiding Theoretical Framework and Worldview

The theoretical framework for this study was based on the Contextual Model of Family Stress (Boss, 2002), an adapted version of the Double ABCX model of family adaptation (McCubbin & Patterson, 1983), and influenced by the cognitive theory of stress and coping (Lazarus & Folkman, 1984) and Mash and Johnson's determinants of caregiver stress (Mash & Johnston, 1983; Mash & Johnston, 1990). The Double ABCX model was the basis for the majority of research concerning family stress and adaption. More recently, the Contextual Model of Family Stress has been used to highlight the contextual factors that influence family stress that are internal and external to the family, including the structure of the family and the cultural context of the family which can greatly influence how a family handles stress (Boss, 2002). Lazarus and Folkman's (1984) cognitive model of stress and coping emphasized the interplay between caregivers' appraisals of stressful events and caregivers' experience of stress. Mash and Johnston (1983; 1990) emphasized the circumstances that can affect stress related to caregiver-child interactions, such as child and caregiver characteristics, and the larger family and social environment. Recently, mixed methods researchers Turner and Johnson (2010) highlighted the literatures on family adaptation and individual stress overlap considerably, but both are needed to best understand how to promote positive family functioning from a family systems framework. All of these theories have helped frame our understanding of caregiver stress related to raising a child with a disability (Hassall & Rose, 2005) and were integrated for use as a framework for this study (see Figure 1 on page 14 for a visual representation).

The framework for this study was situated within the ecological systems theoretical perspective proposed by Bronfenbrenner (1979; 1986). Ecological systems theory has posited children develop within the context of the systems that surround them, which bidirectionally influences their development. One particular subsystem is the parent-child relationship within the family system. From ecological systems theory, positive child development can be promoted by helping to support the family system as a whole. It is from this perspective that the Conceptual Model of Family Stress and the framework for the current study are situated. It was expected that caregivers can be supported, through decreasing caregiver stress and increasing their sense of competence by participation in the psychoeducational support group, in order to promote positive child outcomes and quality child-caregiver interactions.

The current study took a mixed methods case study approach to investigating caregivers' experiences of the psychoeducational support group, using both individual case studies and multiple case studies to answer specific research questions. The research paradigm of mixed methods has largely been attributed to the worldview of pragmatism. Pragmatism highlights the importance of the research question guiding the choice of methodologies; methods are chosen based on what will best answer the proposed research question (Creswell & Plano Clark, 2011). Practicality takes centre stage. Ontologically, pragmatism has purported both singular and multiple realities are typically inherent in quantitative and qualitative research respectively. As a result, both quantitative and qualitative methods have value from a pragmatist's perspective, and can be integrated using mixed methodology to answer research questions without ontological, epistemological, and axiological contradictions. As such, in addition to ecological systems theory, this mixed method study was based on a pragmatic worldview (rather than a case study using qualitative and quantitative approaches).

Role of the Researcher

In a mixed methods case study, that includes a qualitative data strand, the researcher is the primary instrument for data collection, analysis, and interpretation (Creswell, 2003; Stake, 1995). Therefore, as the primary researcher, I needed to acknowledge my own subjectivity in the research process and be self-aware about my own worldview and biases. In order to address my own biases and subjectivity, several approaches were taken to promote research reflexivity. Reflexivity refers to the "process of reflecting critically on the self as researcher, the 'human as instrument'" (Lincoln & Guba, 1985, p. 183). I attempted to be overt regarding my experiences, assumptions, theoretical framework, and worldview, which can all affect the credibility of interpretations of the data. I wrote debrief notes and journal reflections throughout the research process to critically reflect on my own bias, experiences, and challenges. Memos were written when analyzing the qualitative data, which was involved in the reflexive process. In particular, my background is primarily in quantitative research. These experiences affected how I was involved with a mixed methods research study and were therefore critically examined throughout the reflexive process.

My interest in intervention programs for caregivers of children with FASD began with a school psychology doctoral class on evidence-based practice. For this class, myself and two other students surveyed and reviewed current practices, resources, and research on FASD. We talked with several community members and organizations, including the *Coaching Families* team, about services that are available for individuals with FASD and their families, as well as current policies and family needs. In collaboration with community members, the other students and I looked at other areas of research to support an intervention that may be helpful for caregivers of children with FASD. The intervention focused on a workshop for parents of children with FASD. Since this class, I developed a keen interest in evaluating a similar intervention, based on a perceived need and the hopes that the research may help caregivers of children with FASD in some way. This interest was largely based on my general research focus on the social and emotional development of young children and the factors that help facilitate positive development, including positive parent-child relationships. This was achieved within the context of a community-based research and evaluation (CBRE) project, which provides all stakeholders with the opportunity for working collaboratively to help focus on research questions that are of practical use to communities and to help facilitate change. See Appendix A for more information related to the specific CBRE context for the current research project, the participation of all members given the CBRE nature of the project, as well as information related to my own perspectives and experiences of the process.

CHAPTER TWO

Review of the Literature

Being a parent is a challenging role. All parents need different types of supports at different developmental stages. This is particularly true for caregivers of children with FASD. The negative impact of primary caregiver stress on parenting behaviours in can influence positive child outcomes (Minnes, Woodford, & Passey, 2007; Plant & Sanders, 2007). Furthermore, caregiver stress has been related with lower levels of caregivers' sense of competence (e.g., McBride, 1989; Scheel & Rieckmann, 1998). Caregivers' sense of competence is important because caregivers' with higher perceived competence believe themselves to be more effective in difficult situations, and are more open to the possibilities of change, which influence their use of positive parenting practices (Coleman & Karraker, 1998). Understanding the ways in which caregivers can be supported to decrease caregiver stress and increase caregivers' sense of competence are essential to helping families with children with FASD.

This review of the literature presents themes related to family stress research and caregivers' experiences of raising a child with FASD. Included in the review is an overview of an integrated family stress model, primary disabilities and adverse outcomes associated with FASD, caregiver stress, caregivers' sense of competence, and respite as well as family social support. Interventions for children of FASD and caregiver-focused interventions are also reviewed. The chapter closes with a review of mixed methods studies in the area and information concerning the present study and research questions.

Theories of Family Stress and Adaptation

The ABCX model of family stress and adaptation was the basis for most family stress models, and therefore Hill has been named the father of family stress theory (Boss, 2002). Hill's model provided a three-stage model of pre-crisis variables of family stress, which were provided in Hill's work in 1949 but not labeled until 1958. The first stage of the model was posited as (A) the crisis-precipitating event and stressor, which is considered a situation that a family has little preparation for and finds at least somewhat problematic (Hill, 1958), such as child characteristics and behaviours which may pose additional stress on the family. In general terms, family stress has been defined as pressure or tension within the family system that has the potential to change aspects of the system (Boss, 2002). Families experience stressors differently based on the complications associated with stressful situations and what resources each family possesses. The family's available resources are the second stage (B) of Hill's model. Hill defined resources as elements that either help or hinder the family to address stressful situations. Both stress and families' resources to address the stressor interact with Hill's third stage (C), which was outlined as the definition, appraisal, or interpretation of the stressor by the family. The final stage of Hill's model was the precipitation of a family crisis, which can extremely influence family roles, patterns, and routines, although not all families reach this final stage.

A limitation of Hill's (1958) work was that it only included stages of pre-crisis elements with no overview of how these variables may fluctuate following a crisis. It also proposed a somewhat linear model, which does not reflect families' experiences of moving to and from phases of stress that greatly affects its usefulness for intervention design and implementation. However, Hill's model did include families' appraisals of the events, which is an important element for understanding family adaptation and stress, as highlighted by Lazarus and Folkman's (1984) cognitive model for stress and coping. The cognitive model has underscored the importance of individual family members' cognitions for influencing the family experience of stress, and its interaction with the environment. As Lazarus and Folkman (1984) defined, stress is "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). It is the appraisal of this relationship that can affect the experienced level of stress by a primary caregiver. Research on experiences of stress of caregivers of children with Autism Spectrum Disorder (ASD) has highlighted that positive appraisals of stressful situations can help to protect caregivers against heightened levels of stress (Hassall, Rose, & McDonald, 2005).

McCubbin and Patterson (1983) extended Hill's (1958) ABCX model to include post-crisis events, including the pile-up of stressors, resources, and perceptions, to better understand why some families were able to adapt to stress, while others had difficulty doing so (Patterson, 1988). The added elements to the model of family stress can further our understanding of the more complete process of stress experienced by families. This model has been particularly useful in guiding research investigating caregiver stress related to caring for a child with a disability and identifying variables that protect families from high levels of stress and instead promote families' successful adaptation (Hassall et al., 2005). For example, social support and active coping strategies have been found to be helpful variables whereas additional stressors and maternal negative appraisals of their children's disability were found to be risk factors for mothers of children with ASD dealing with stress (Bristol, 1987). Additionally, Saloviita, Italinna, and Leinonen (2003) illustrated the importance of this model by using it to identify several variables that accounted for the majority of parental stress experienced by both mothers and fathers, with the most important predictor being a negative definition or appraisal of the situation. The Double ABCX model and subsequent research has moved away from the traditional view that child characteristics are the sole source of family stress, and emphasized the bidirectional nature of family adaptation by including caregiver appraisals and beliefs.

The Contextual Model of Family Stress (Boss, 2002), which incorporated these elements and was based on the Double ABCX model, is most helpful for the design and implementation of a caregiver-focused intervention. Like other models based on the Double ABCX model, this model has focused on three elements that interact to impact family adjustment for families raising a child with a disability: (a) the characteristics and experiences of raising a child with disabilities, (b) interpretations and making of meaning of the situation, and (c) resources, supports, and self-appraisals available to the family (Turner & Johnson, 2010). It is these elements that have helped guide research and have been largely supported by research of parents with children with disabilities (e.g., Frey et al., 1989; Hassall & Rose, 2005; Saloviita et al., 2003).

More specifically, the Contextual model highlighted the factors associated with family stress, both internal and external to the family. Internal factors include aspects in which the family has control, such as the structural context of family roles, the families' perception of the event, and the families' values and beliefs. These factors bidirectionally influence each internal aspect of the family as well as the perception of a stressful event or situation. External ecological factors include cultural, historical, and economical context in which the family is situated, which influences internal family characteristics, beliefs, and values. Caregiver stress, sense of competence, support, and knowledge can all be attributed to the internal factors associated with family stress. Furthermore, Mash and Johnston's (1983, 1990) investigations into the determinants of caregiver-child interactive stress provided support to the internal factors that can influence family stress. Mash and Johnson (1983, 1990) emphasized additional parent, child, and environmental characteristics that influence family stress in the context of caring for a child. For instance, when examining the determining factors that influence family stress when caring for a child with externalizing behaviours, Mash and Johnston (1983, 1990) found family stress to be influenced by child characteristics but mediated by caregiver cognitions. Maternal perceptions, appraisals, and self-efficacy were all indicated to be important factors when examining caregiver stress.

Common to both the Contextual model (Boss, 2002) and Mash and Johnston's (1983, 1990) research is the importance placed on both family and individual characteristics. Conceptually, family stress research has been concerned with changes in the family system whereas individual stress research has focused on changes in the individual body. Individual stress research has also called attention to individual cognitive factors that can influence the experience and expression of stress, such as how appraisals influences stress levels (Lazarus & Folkman, 1984). As such, models from individual and family stress research, including the Contextual Model of Family Stress (Boss, 2002), Lazarus and Folkman's (1984) cognitive theory of individual stress, and Mash and Johnson's (1983, 1990) determinants of caregiver stress, created an appropriate guiding framework for the research study (see Figure 1 for visualization).

Primary Disabilities and Adverse Outcomes Associated with FASD

Compared to other areas in developmental research, such as research on ASD, the study of FASD as a disorder is relatively recent. Jones and colleagues first termed the pattern of neurological and physical abnormalities associated with maternal alcohol consumption as Fetal Alcohol Syndrome only four decades ago (K. L. Jones & Smith, 1973; Lemoine, Harrouseau, Borteyru, & Menuet, 1968). Since this time, there has been much debate about the most appropriate nomenclature related to FASD and associated disabilities (e.g., Miller, 2013).

Guidelines for the diagnosis of FASD in Canada have been developed (Chudley et al., 2005) and are based on a four-digit diagnostic code (Astley & Clarren, 1999). Individuals are

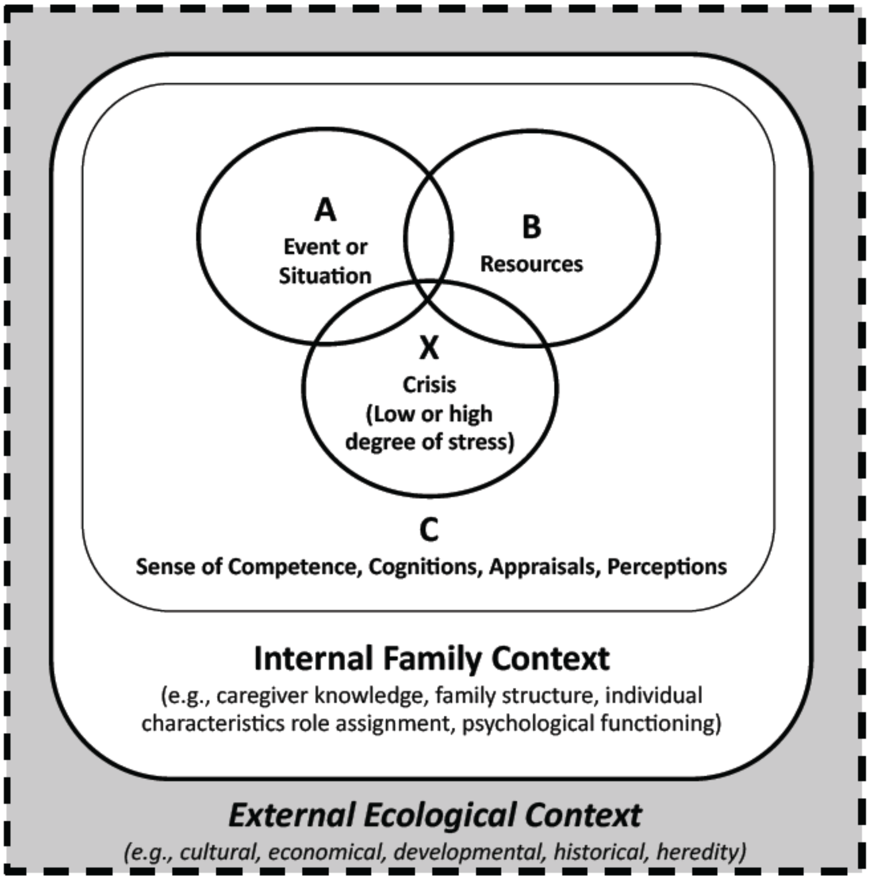

Figure 1. Theoretical framework adapted from the Contextual Model of Family Stress (Boss, 2002), the cognitive theory of stress and coping (Lazarus & Folkman, 1984), and the determinants of caregiver stress (Mash & Johnston, 1983; Mash & Johnston, 1990)

screened and then assessed in four areas: growth deficiencies, facial features, central nervous system damage, and gestational exposure to alcohol. Ranking scores on each area range from one to four. Prenatal alcohol exposure (PAE) produces a range of effects with associated diagnostic terms: Fetal Alcohol Syndrome (FAS), Partial FAS, Fetal Alcohol Effects (FAE), Alcohol-

Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defeats (ARBD, Chudley et al., 2005).

FASD[2] has evolved to become an umbrella term used to denote a set of more specific diagnoses that reflect a range of effects that occur in individuals that have been prenatally exposed to alcohol. These effects can be subtle or serious, with affected individuals presenting variable combinations of life-long deficits in memory, information processing, attention, motor skills, executive functioning, academic skills, and social skills, as well as significant behavioural and mental health issues (e.g., Bertrand et al., 2004; Manji, Pei, Loomes, & Rasmussen, 2009; O'Connor et al., 2002; Streissguth, Randels, & Smith, 1991). Although our understanding is far from complete, research concerning the complex deficits associated with FASD has steadily increased over the last four decades.

It is well established that prenatal exposure to alcohol can damage a developing fetus and can result in a complex range of neurodevelopmental disabilities (Jones, Smith, Ulleland, & Streissguth, 1973; Warren et al., 2004). The national prevalence of FASD in Canada is estimated to be nine cases per 1000 infants born based on extrapolation of data from the United States that suggests similar rates (Chudley et al., 2005). However, recent international data from school-based screening and diagnosis studies has suggested the overall incidences are probably higher (Institute of Health Economics, 2009), particularly because diagnosis can often be delayed or missed. Additional data from smaller rural communities in Canada indicates prevalence may be higher in some areas (e.g., Chudley et al., 2005; Habbick, Nanson, Snyder, Casey, & Schulman, 1996; Robinson, Conry, & Conry, 1987; Square, 1997; Williams, Odaibo, & McGee, 1999).

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[2] The term FASD has been used throughout the current document. In some instances, the literature reviewed has used different vocabulary, such as FAS or FAE; however the term FASD has been used throughout as an umbrella term for the sake of consistency.

The Institute of Health Economics (2009) indicated that the estimated annual economic cost of FASD in Alberta is between $130 and $140 million per year. Currently, it is estimated the annual cost in Canada of supporting individuals from birth to 53 years with FASD is $5.3 billion (Stade et al., 2009). Included in this cost is spending for educational, medical, and social services. Significant determinants of the cost included the severity of the individual's condition, age, and relationship of the individual to their caregiver (i.e., biological, adoptive, or foster). More specifically, costs for children with FASD were greater when they were in care than with adoptive or biological caregivers, and in this study the majority of children under the age of 1 were in the care of a child protection agency. Previous estimates of the cumulative life-long cost for those living with FASD in Canada was $600 billion (Institute of Health Economics, 2009), with sixty percent towards educational and medical spending, including addictions and drug treatments, and the remaining costs towards social services, housing, and the justice system, as well as financial costs to families. The needs of individuals affected by FASD generate considerable challenges to communities and expense to social welfare, educational, medical, and correctional services (Institute of Health Economics, 2009). The personal cost to individuals and families is immeasurable.

No one neuropsychological profile can characterize all individuals with FASD; a wide range of cognitive, behavioural, and social difficulties have been documented for children with FASD (Greenbaum, Stevens, Nash, Koren, & Rovet, 2009; Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998). Core areas of psychological deficits typically include such areas as learning, memory, information processing, attention, language, arithmetic, executive functioning (including planning and cognitive flexibility), and intellectual disability (e.g., J. L. Jacobson & Jacobson, 2002; O'Connor et al., 2002; Pei & Rinaldi, 2004; Rasmussen, Horne, &

Witol, 2006; Streissguth et al., 1991). Preschool children with FASD may display disinterest in food, disrupted sleep, poor motor coordination, and expressive language delays. They may also be overly friendly and more interested in people rather than objects (Graefe, 1998). During the early school period, children with FASD may have more difficulties with arithmetic than with spelling and reading, as during the first two years of school reading and writing may not be noticeably delayed. As classroom demands increase, attention and impulse control difficulties may become more apparent.

Learning and memory problems are often reported in children with FASD (Roebuck-Spencer & Mattson, 2004), which may help to explain why children with FASD often have significant levels of academic underachievement (Howell, Lynch, Platzman, Smith, & Coles, 2006). Past research has indicated children with FASD experience particular difficulties with verbal learning, which has implications for classroom instruction (Roebuck-Spencer & Mattson, 2004). Additionally, reinforcement learning may take longer for children with FASD and is more dependent on recent information. If given sufficient and consistent repetition, children with FASD may be able to learn from reinforcement learning, based on a study by Engle (2008).

Executive functioning has been defined as higher-order cognitive processes, including planning and attention systems, involved in goal-oriented behaviour under conscious control (Rasmussen, 2005; Zelazo & Muller, 2002). In previous studies, children with FASD have demonstrated deficits with executive functioning (Kodituwakku, Kalberg, & May, 2001). Interestingly, difficulties with verbal tests of executive functioning seem to be more pronounced with age. Children with FASD have also demonstrated significant impairments in the area of information processing (Graefe, 1998). Since many areas of daily functioning can be affected, children with these difficulties often have behavioural, social, and emotional problems as adverse outcomes.

Primary deficits vary in severity, and may interact with environmental factors to contribute to the development of adverse outcomes (Streissguth et al., 2004). Adverse outcomes for children with FASD can include additional diagnoses of Attention Deficit Hyperactivity Disorder (ADHD), Attachment Disorder, Oppositional Defiant Disorder, or Conduct Disorder (Graefe, 1998). Depressive symptoms are also common for this population, and have been noted in children as young as five- or six-years-old (O'Connor & Kasari, 2000). Children with FASD may also have a disrupted school experience, difficulties with the law, alcohol or drug problems, inappropriate sexual behaviour (Streissguth et al., 2004), or difficulties with communication and daily living skills (Graefe, 1998). Although further research is needed, recent research on animal models has suggested that some adverse outcomes associated with FASD may in fact be primary deficits associated with prenatal exposure to alcohol. More specifically, the effects of prenatal alcohol may cause the dysregulation of the hypothalamic–pituitary–adrenal axis, which is a key player in the stress response and anxiety/depression symptoms (Hellemans, Sliwowska, Verma, & Weinberg, 2010; Weinberg, Sliwowska, Lan, & Hellemans, 2008).

FASD can occur in all sections of society. Birth mothers of children with FASD come from diverse ethnic and economic backgrounds. However, in a five-year follow-up study conducted in Washington state, birth mothers were often found to experience mental health difficulties, were socially isolated, and were victims of abuse (Astley, Bailey, Talbot, & Clarren, 2000). Additionally, poverty, genetics, maternal stress, and poor nutrition are possible risk factors and can influence the severity of FASD (Institute of Health Economics, 2009). As Chudley and colleagues (2005) indicated, other risk factors for prenatal alcohol exposure include lower socioeconomic status, higher maternal age, lower maternal education level, cocaine and smoking prenatal exposure, paternal alcohol and drug use at the time of pregnancy, and custody changes. The number one protective factor for children with FASD is living in a stable, nurturing home, with early identification and diagnosis being an additional protective factor (Olson et al., 2009; Streissguth et al., 2004).

Streissguth and colleagues (2004) conducted life history interviews about past and current events with adoptive, foster, and biological caregivers of individuals with FASD. Five adverse life outcomes were derived from the interviews. Streissguth and colleagues found that adolescents and adults with FASD had lifetime prevalence rates of 61% for disrupted school experiences, 60% for trouble with the law, 50% for confinement (such as detention, prison, or psychiatric or rehab inpatient settings), 49% for inappropriate sexual behaviours, and 35% for alcohol and drug use problems. Twenty percent of individuals with FASD were raised by their biological mothers, 33% were raised by adoptive parents, and 25% were raised by their fathers, foster parents, or stepparents. Two important protective factors were found for ameliorating these adverse life outcomes: receiving an early diagnosis of FASD and being reared in a stable home environment. These two protective factors increased the chances of escaping the five adverse life outcomes for individuals with FASD by 2- to 4-fold. A stable home environment was the most influential protective factor against trouble with the law, disrupted school experience, alcohol and drug use problems, and inappropriate sexual behaviour. As Streissguth and colleagues state, "good stable families, with enduring relationships with their children with FAS/FAE, appear to be a critical protective factor for helping children avoid adverse life outcomes" (p. 237). The longer the time spent in a stable home environment, the smaller the risk for these adverse life outcomes. These results highlight the importance of collaborative interventions between families, communities, and practitioners that help to support caregivers provide stable, nurturing home environments for children with FASD.

Despite Streissguth and colleagues' (2004) findings, and other research that has suggested high rates of environmental risk for children with FASD (Olson, Jirikowic, Kartin, & Astley, 2007), little is still known about the role of family factors plays in life outcomes for children with FASD. Olson and colleagues (2009) have provided an overview of the small amount of systematic research that has investigated family factors and outcomes. Nevertheless, the available research has underscored the important role the family environment can play in the development of children with FASD. For instance, Coggins, Timler, and Olswang (2007) found that children with FASD had disproportionally higher levels of negative or unpredictable home environments, such as multiple foster home placements or caregivers dealing with mental health issues, and this risk factor may negatively affect children's development of social communication abilities. The quality of caregiving for children with FASD has also been found to be a moderator for children's cognitive development (Jacobson, Jacobson, Sokol, Chiodo, & Corobana, 2004). Further research is needed to understand this complex relationship.

Caregivers' Experiences of Raising a Child with FASD

Families most often shoulder the responsibility of providing care and support for children with FASD. The number one protective factor for children with FASD against adverse outcomes and negative child outcomes is living in stable, supportive homes (Olson et al., 2009; Streissguth et al., 2004). However, caring for a child with FASD includes many stressors above and beyond what is typically associated with raising a child. The cognitive deficits, behavioural difficulties, and possible adverse outcomes associated with FASD create a considerable challenge for caregivers (Brown & Bednar, 2003). As Giunta and Streissguth (1988) explained:

> The caretaker of a child with FAS assumes a responsibility far beyond that normally associated with parenting. The constellation of physical, intellectual, and behavioural characteristics that typifies patients with FAS can create a very demanding situation for a caretaker. These patients often require constant supervision; they are described by successful caretakers as requiring an extraordinary amount of time, energy, love, and, most of all, consistency. These caretakers need support in their efforts. (p. 458)

Several qualitative, quantitative, and mixed methods studies have explored the experiences of adoptive, foster, and biological caregivers of children with FASD. Qualitative studies have explored adoptive (Granitsas, 2004), foster (Gardner, 2000), and biological (Sanders, 2008) caregivers' experiences. Using quantitative cluster analysis, Brown and Bednar (2004) analyzed information gathered from interviews with adoptive and foster caregivers of children with FASD. Using both qualitative and quantitative data sources, McCarty and colleagues (1999) investigated caregivers' experiences of adopting a child with FASD and Mukherjee, Wray, Commers, Hollins, and Curfs (2013) investigated the impact of raising a child with FASD within the United Kingdom context. These studies have highlighted the needs and challenges of caregivers raising children with FASD, but research is still needed to better understand what aspects of interventions caregivers find helpful for creating supportive home environments.

Experiences of caregivers of children with FASD appear to have mixed rewards and challenges. The next few studies capture that range of perspectives. First, in a study by Granitsas (2004), four adoptive caregivers of children with FASD were interviewed. The results revealed six themes: (1) feelings of delight upon adopting their child or children; (2) not knowing about the child's diagnosis or being given misinformation; (3) identifying problems, concerns, and difficulties that are common to FASD; (4) feeling frustrated associated with difficulties of raising a child with FASD; (5) feeling pride in their children's accomplishments; and (6) feeling devoted despite any difficulties. Granitsas also spoke of her own experiences raising four adoptive children with FASD, and how her experiences resonated with the experiences described by participants. Based on her own and the participants' experiences, Grantisas recommended nurses should learn about effective prevention and intervention programs for families with FASD in order to be good resources for caregivers. In order for service providers to become effective advocates for families they require education about FASD.

Another example of the variability of experiences was found in a study by Gardner (2000). Gardner conducted interviews with eight foster mothers to explore their experiences of raising a child diagnosed with FASD. The results formed into three categories: (1) cognitive concerns, (2) issues with behaviours management, and (3) problems with daily living. All of the foster caregivers described experiences associated with their children's difficulties with their memory and comprehending information. Several of the foster caregivers indicated that at times the children did not understand the consequences of their behaviour or had a diminutive sense of fear, which could be very frightening for the foster caregivers. Foster caregivers spoke of the children as being hyperactive, aggressive, and sometimes destructive. Associated with the children's diminutive feelings of fear, foster caregivers talked about the children having high levels of pain tolerance. Foster caregivers' were concerned with providing consistency and stability in daily living, ways of developing coping strategies, and fears concerning the child's future. Feedback from foster caregivers led Gardner (2000) to recommend that practitioners are in a position to help caregivers create realistic expectations and to reframe the cause of misbehaviours.

Biological parents also have varied experiences, which can largely overlap with that of adoptive and foster caregiver. Sanders (2008) interviewed seven adoptive, one foster, and three biological caregivers', which provided some additional insights into both biological and non-biological caregivers' experiences of raising a child with FASD. All caregivers' discussed the process of diagnosis as a "double-edged sword" (p. 37), with caregivers experiencing feelings of guilt, grief, and relief. Caregivers also talked about feelings of anger toward their child's birth mothers. Both of these findings had not been previously addressed in the literature. Finally, caregivers discussed their role as lifelong parents and the stress associated with this role. Despite these challenges, caregivers often talked about their children's gifts and the positive ways they bring satisfaction to their lives (Sanders, 2008). Consistent with previous research, non-biological caregivers discussed being given incomplete or misinformation regarding their child's diagnosis, and dealing with professionals who often lacked knowledge of FASD. Similar to foster caregivers' experiences described by Gardner (2000), difficulties with behavioural challenges, including tantrums and aggression, and memory difficulties were indicated as particular challenges. In particular, one caregiver described living with their child as "living in a war zone" (p. 44). However, many caregivers discussed how learning about FASD and its associated behaviour and cognitive deficits helped them to feel more competent as caregivers despite barriers when accessing support.

An addition to the literature on the experiences of caregivers has evolved to examine the complex systems of care in which caregivers may access information and supports. Walls and Pei (2013) investigated caregivers' experiences of systems of care (e.g., health, education, mental health, and respite services) by interviewing six adoptive caregivers and two foster caregivers. Grounded theory analysis of these interviews indicated four stages of caregiving for children with FASD: (1) problem identification and information gathering about FASD; (2) questioning, self-doubt, and reflecting on parenting practices; (3) collaborating with professionals and restructuring family life; and (4) reaching a stage of acceptance. Service needs of families changed as a function of these stages. Results also indicated several challenges to program delivery, including long wait lists, age restrictions, high rates of staff turn over, and restrictive funding guidelines. Additionally, caregivers reported having services provided in a centralized location would be beneficial in order to eliminate the duplication of services, having to recite the families' FASD story multiple times, reduce travel time, and be a place to connect with other families.

Alternatively, little quantitative research has investigated caregivers' experiences of raising children with FASD. Several qualitative (Gardner, 2000; Granitsas, 2004; Sanders, 2008) studies have indicated caregivers experience significant barriers and challenges raising children with FASD. Brown and colleagues (e.g., Brown & Bednar, 2004; Brown, Bednar, & Sigvaldason, 2007) studied both adoptive and foster caregivers' challenges and needs when raising children with FASD. Brown and Bednar (2004) researched the challenges of 19 adoptive, foster, and biological caregivers faced when raising children with FASD by creating concept maps from cluster analysis, which yielded eight categories. Caregivers reported challenges of ameliorating setbacks in the children's behaviour, making and keeping both immediate and long-term plans, home-school collaboration, keeping their children's involved social activities, communicating with professions, and behaviour management. All of these clusters were consistent with previous qualitative literature regarding caregivers' experiences, with the exception of one finding: participants' reported accounts of working with professionals whom they felt did not demonstrate respect for caregivers raising children with FASD. These results broaden our understanding of caregivers' experiences and the challenges they face when raising a child with FASD.

Using both quantitative and qualitative sources adds a different dimension to research of caregivers' experiences of raising a child with FASD. McCarty and colleagues (1999) conducted one of the first studies that explored caregivers' experiences, and included both qualitative and quantitative data sources. These researchers interviewed 20 adoptive caregivers four months and one year after they adopted a child with FASD and asked caregivers to complete a parenting stress measure (i.e., Parenting Stress Index [PSI], Abidin, 1995) four months after adoption. Interview data indicated caregivers' often found satisfaction when caring for their child with FASD. However, both interview and questionnaire data also indicated caregivers experienced high levels of stress; caregivers found parenting to be much harder than they had expected. McCarty and colleagues suggested caregivers' difficulties could be attributed to multiple factors, including children's behaviour associated with prenatal exposure to alcohol and the effects of multiple placements for children prior to being adopted, as well as possible lack of parenting experiences of new caregivers. From these findings, these researchers recommended a variety of services for caregivers due to the diversity of needs of families. In particular, education about FASD and support groups where concerns can be explored would be helpful for caregivers.

Furthermore, Mukherjee and colleagues (2013) mixed qualitative focus group information and quantitative survey data (i.e., PSI, Abidin, 1995) to better understand caregivers' experiences of raising a child with FASD within the United Kingdom context. Eight themes arose from this mixed methods study: (1) parenting a child with FASD is a very unique experience; (2) adoptive caregivers felt they had not received adequate information when adopting; (3) a lack of knowledge among professionals; (4) having to "fight" (p. 50) to obtain needed support; (5) feeling misunderstood or betrayed due to a lack of knowledge; (6) feeling blamed and a lack of support increased their feelings of stress; (7) feeling isolated; and (8) having concerns about the future. Several qualitative themes were reportedly supported with PSI data. More specifically, decreased feelings of competence (i.e., competence subscale) may be related to parenting a very unique child (i.e., theme one), stress related to child characteristics (i.e., child domain subscales) was exacerbated by feeling misunderstood or blamed (i.e., theme six), lack of support (i.e., theme four) put extra strain on relationships with partners (i.e., relationship with spouse subscale), and finally, qualitative reports of isolation was also reiterated by high ratings of this subscale (i.e., isolation subscale). These results reinforce previous themes obtained within the North American contexts.

The reviewed studies have outlined caregivers' experiences and challenges related to their children's memory, comprehension, and behavioural difficulties associated with FASD (Gardner, 2000; Sanders, 2008), as well as worries regarding their children's development and future (Gardner, 2000). Caregivers have also described barriers related to receiving a diagnosis and accessing services (Granitsas, 2004; Sanders, 2008; Whitehurst, 2012). These studies suggested the important role service providers can play to help caregivers find resources and be advocates when families are dealing with health, education, and legal systems (Granitsas, 2004; McCarty et al., 1999; Sanders, 2008). It is particularly important that service providers receive education regarding FASD, as one of the most concerning experiences described by caregivers was dealing with professionals who lack a sufficient knowledge of FASD and respect for caregivers (McCarty et al., 1999).

Caregiver needs. Brown and colleagues (e.g., Brown & Bednar, 2004; Brown et al., 2007) further explored caregivers' perspectives about what they feel they need to be good parents. Brown and Bednar (2003) interviewed 19 foster, adoptive, and biological caregivers. Using concept maps, results included several needs: having support networks; having a wide range of services, including crisis management and recreation programs; and working with professionals who are empathetic, respectful, and knowledgeable about FASD. Caregivers described internal needs, such as the necessity to develop behaviour management skills and to recognize that each child is unique, which could be fostered by strengths-based services. Many of these results reiterate previous findings, however caregivers' indicated the usefulness of the Internet when accessing information and community resources, which had not been previously outlined.

One of the pivotal findings was that foster caregivers indicated they require sufficient financial resources, respite, and certain personal and parenting styles for supporting a child with FASD in a successful placement (Brown et al., 2005). For instance, caregivers require strong organizational skills in order to provide structure and clear limits for children. As Giunta and Streissguth (1988) state, "foster parents who are calm and low-key individuals, secure and comfortable with themselves and who live stable and predictable lives, have the highest likelihood of success" (p. 457). Foster caregivers reiterated the need for support networks that includes other foster caregivers and competent professionals. Foster caregivers also highlighted that if their efforts were taken for granted, the child harmed someone in the home, or the child could not adapt to the household routines, the placement may break down (Brown et al., 2007). Despite these needs and challenges, several motivating factors influence foster caregivers to foster children with FASD. According to Brown et al. (2007), these motivations include wanting to make a positive change and contribution to the welfare of children with FASD; confidence in their own parenting; a feeling of obligation; and the ability to drawn on their own parenting experiences. Similar to what motivates foster caregivers of children with special needs, foster caregivers of children with FASD are motivated by a desire to help children and emphasized the positive aspects of fostering children with FASD (Brown et al., 2007).

Caregivers' needs share commonalities, while also being distinct. A study conducted by Huculak and McLennan (2009) revealed needs specific to caregivers of children with FASD living in Alberta, including services for life skills development and peer support (Huculak & McLennan, 2009). Caregivers have found it difficult to access services for behaviour difficulties not necessarily unique to FASD, such as hyperactivity and life skills development. Life skills development was a particular concern for caregivers of older adolescents or young adults. Interestingly, caregivers also indicated a preference for support from other caregivers of children with FASD, rather more formalized services, and spoke highly of caregiver-mentor programs and parents support group services. Caregivers spoke of positive experiences of being in the company of other caregivers knowledgeable of FASD in order to learn from their experiences and to feel supported rather than feeling judged. These experiences highlight the important role group interventions can play in helping to address the needs of caregivers.

Although some studies have illuminated the needs and challenges of caregivers of children with FASD, what remains to be investigated are the experiences of families raising children with FASD and what services they have found helpful and impactful for creating a supportive home environment (Olson, Rudo-Stern, & Gendler, 2011; see below). Both practitioners and researchers must be aware of the needs of caregivers in order to effectively target interventions and interventions research. Caregivers have suggested intervention researchers should collaborate with caregivers in order to design effective and valuable interventions for families through consultation with caregiver advocacy groups (Devries &

Waller, 2004; Ryan, Bonnett, & Gass, 2006) as used in the community-based research approach. Caregivers reiterated several needs, two of which are particularly important for the current study. First, caregivers have asked for a wide range of services for both their children and their families with professionals who prove to be empathetic, respectful, and knowledgeable about FASD (Brown & Bednar, 2003; Brown et al., 2005). In particular, caregivers in Alberta have praised programs that have helped them to enhance their support networks (Brown & Bednar, 2003; Huculak & McLennan, 2009; McCarty et al., 1999). Second, caregivers have highlighted that they must learn about FASD, including behavioural management strategies, in order to be effective caregivers for their children (Brown & Bednar, 2003; Brown et al., 2005; Brown et al., 2007; McCarty et al., 1999). In order to address these specific needs and extend the current literature, the current study investigated a psychoeducational support group for caregivers.

Helping to create supportive homes is important as it helps to ameliorate adverse outcomes for children with FASD (Olson et al., 2009; Streissguth et al., 2004) and caregivers' often experience high levels of stress when caring for a child with FASD (McCarty et al., 1999; Paley et al., 2005; Sanders, 2008). Caregiver stress has been shown to negatively affect parent-child relationships and child outcomes (Minnes et al., 2007; Plant & Sanders, 2007). As stated previously, the Contextual Model of Family Stress (Boss, 2002) posited that family stress is the product of the interaction between the internal aspects of the family (e.g., values, beliefs), the way family members appraise the stressor, and family members' available resources. This argument has been supported by research that has suggested caregiver stress is impacted by both caregivers' sense of competence (i.e., an internal factor) and social support (i.e., a family resource; e.g., McBride, 1989; Raikes & Thompson, 2005; Scheel & Rieckmann, 1998; Sepa, Frodi, & Ludvigsson, 2004). Caregiver stress is intertwined with many other caregiver variables, including caregiver sense of competence, perceived knowledge, and support, all of which can positively affect caregiver-focused intervention outcomes (Pottie & Ingram, 2008; Pottie et al., 2009; Singer et al., 2007). These factors may all interact to influence families' quality of life. Research pertaining to the levels of stress, sense of competence, support, and quality of life experienced by caregivers' of children with FASD is presented.

Caregiver stress. Many studies have documented the increased levels of stress caregivers' feel raising a child with a disability (Baxter et al., 2000; Belsky, 1984; Saloviita et al., 2003; Tomanik, Harris, & Hawkins, 2004). Adoptive, foster, and biological caregivers of children with FASD have significantly higher levels of parental stress that is typically associated with raising a child (Paley et al., 2005; Sanders, 2008). Watson, Coons, and Hayes (2013) found caregivers of children with FASD had significantly higher stress levels than caregivers of children with ASD, as measured by the Parenting Stress Index – Short Form (PSI-SF, Abidin, 1995). Both caregivers' of children with ASD and FASD experience significant amounts of stress, but experience distinct stressors (Watson, Hayes, Coons, & Radford-Paz, 2013). In interviews, Watson, Hayes, Coons, and Radford-Paz (2013) found both groups discussed difficulties with obtaining a diagnosis, accessing services, dealing with challenging behaviours, and playing multiple roles as caregivers; however, caregivers' of children with FASD discussed the lack of understanding, supports, and specialists for FASD, as well as their children's illegal behaviour.

Additionally, primary caregivers of children with FASD may not possess adequate resources or support. For instance, caregivers often have to advocate for their child to receive services from multiple sites (Ryan et al., 2006; Watson et al., 2013). Fewer resources and support has been shown to exacerbate stress levels of primary caregivers of children with FASD (Paley, O'Connor, Frankel, & Marquardt, 2006). High levels of caregiver stress can negatively affect the quality of caregiver-child interactions that are central to child development (Minnes et al., 2007; Plant & Sanders, 2007), and may even cause the breakdown of a foster placement for a child with FASD (Brown et al., 2007). FASD carries an additional burden because it is a condition that could have been prevented (Olson et al., 2009). Stress may influence caregivers to respond to their child in a way that actually aggravates their child's difficulties, which in turn may heighten caregiver stress and increase the risk for caregiver burn out (Paley et al., 2006). Caregiver stress is often related to higher levels of children's externalizing problems (e.g., Paley et al., 2005), such as fighting or violating the rights of others, family maladjustment (e.g., Plant & Sanders, 2007), and lower levels of caregivers' sense of competence (e.g., McBride, 1989; Scheel & Rieckmann, 1998).

Several of the previously reviewed qualitative studies highlighted the high level of stress experienced by caregivers of children with FASD. For instance, Granitsas (2004) summarized caregivers' feelings of frustration, Gardner (2000) outlined caregivers' stress and fear associated with worrying about their children's safety, and Sanders (2008) described that some caregivers feel they are often "living in a war zone" (p. 44). Additionally, in interviews conducted by Brown et al. (2007), foster caregivers spoke of exhaustion from stress and burn out as playing a key role in the brake down of placements for children with FASD.

Quantitative research regarding caregivers stress has produced a preponderance of research that has included the study caregiver stress using the Parenting Stress Index (PSI, Abidin, 1995). Many studies have documented caregivers stress using this measure, for example, for caregivers raising children with ASD (e.g., Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Pottie & Ingram, 2008) and Attention-Deficit/Hyperactivity Disorder (ADHD, e.g., Harrison & Sofronoff, 2002). Both McCarty and colleagues (1999) and Paley and colleagues (Paley et al., 2005; Paley et al., 2006) have documented the high levels of stress experienced by caregivers' of children with FASD.

Paley and colleagues (Paley et al., 2005; Paley et al., 2006) have investigated the predictors of stress for caregivers of children with FASD using the PSI. Using structural equation modeling, Paley and colleagues (2005) found that prenatal alcohol exposure was related to children's externalizing behaviour, which in turn was related to higher levels of caregiver stress. Fewer family resources (such as basic needs, support, and medical care) were also related to higher levels of caregiver stress. More specifically, Paley and colleagues (2006) found children's executive functioning, adaptive functioning, externalizing behaviours, and internalizing behaviours, but not children's cognitive functioning, were significant predictors of caregiver stress. Caregivers' adoptive parent status also increased caregiver stress, which may suggest caregivers were not adequately prepared for the severity of their child's difficulties and behaviours (Paley et al., 2006). These results have implications for implementing family-focused interventions, which may include education about FASD and behaviour management strategies, respite care, and caregiver support groups for decreasing caregiver stress. As Paley et al (2006) state:

> The most effective interventions may be those that not only aim to ameliorate the myriad of cognitive, social, and behavioral difficulties often exhibited by this population of children, but also focus on providing support, education, and training to maximize the well-being and efficacy of their parents and caregivers. (p. 402)

Caregiver sense of competence. Caregiver sense of competence refers to the feelings of parental self-efficacy and satisfaction (Johnston & Mash, 1989), and is sometimes labeled as parenting self-esteem (e.g., Mash & Johnston, 1983) or parenting self-efficacy (e.g., Coleman & Karraker, 1998). Self appraisals of caregiver competence are closely related to feelings of parental self-efficacy, which is broadly defined as the expectations caregivers hold about their ability to parent successfully in the varied tasks associated with this demanding role (Coleman & Karraker, 1998; Jones & Prinz, 2005). Caregivers' self-efficacy is considered a more specific form of a person's overall feelings of self-efficacy (see Bandura, 1977; Bandura, 1997).

Feelings of competence are directly related to caregiver behaviours, caregiver-child relationships, family adjustment, and quality of life (e.g., Hill, 1971; McCubbin & Patterson, 1983). High levels of caregivers' sense of competence has been linked to both competent and positive parenting practices with caregivers with higher self-esteem dealing with their children in warmer, more responsive ways, with less hostility and inconsistent parenting (Coleman & Karraker, 1998; T. L. Jones & Prinz, 2005). Caregivers with higher perceived competence have greater positive expectations related to coping with difficult situations, as well as the possibilities of change, and show greater positive parenting practices, strategies, and behaviours (Coleman & Karraker, 1998). Caregiver sense of competence is also intertwined with caregivers' stress (e.g., Boss, 2002; Crnic & Low, 2002; Hassall et al., 2005; Hassall & Rose, 2005; Raikes & Thompson, 2005). In fact, the PSI (Abidin, 1995) includes a subscale that asks caregivers about how competent they feel.

Understanding feelings of competence for caregivers of FASD is important due to its relationship with parent and child outcomes (e.g., Coleman & Karraker, 1998; T. L. Jones & Prinz, 2005), family stress (e.g., Crnic & Low, 2002), and even motivation (Brown et al., 2007). Despite its importance, few studies have investigated sense of competence for FASD populations and their families. The Parenting Sense of Competence Scale (PSOC), comprised of efficacy and satisfaction subscales, is frequently used to measure caregiver sense of competence (Johnston & Mash, 1989). One FASD intervention has used both the PSI and PSOC scales to measure intervention outcomes (Bertrand, 2009). This intervention used a behavioural consultation approach to increase caregiver self-esteem and reducing children's problem behaviours using a model, although these results are only preliminary.

Using the PSOC, Mash and Johnston have investigated caregiver sense of competence for caregivers of children with ADHD (Mash & Johnston, 1983) and children who have experienced physical abuse (Mash & Johnston, 1990). Mash and Johnston (1983) found a consistent relationship between higher reports of children's behaviour problems and lower levels of caregiver self-esteem, which was replicated by Johnston and Mash (1989) and Coleman and Karraker (2003). Caregivers' feelings of efficacy were also related to their children's age, with caregivers of older hyperactive children having the lowest sense of competence (Mash & Johnston, 1983).

Caregiver education has been found to relate to caregivers' sense of competence (e.g., Ialongo et al., 1999), which is also linked to observed parenting skills (Webster-Stratton et al., 2004) and a reduction in dysfunctional family practices (e.g., Morawska, Winter, & Sanders, 2009). With greater knowledge of parenting and child development, caregivers may feel more equipped to deal with difficult and stressful situations. As Giunta and Steissguth (1988) attested, knowledge of FASD helps to create realistic expectations. Several researchers (e.g., Bertrand, 2009; McCarty et al., 1999) and caregivers (Brown et al., 2007; Sanders, 2008) have emphasized the importance of education for helping caregivers support children with FASD. Little research has examined FASD education and caregiver sense of competence with caregivers of children with FASD, and therefore was incorporated into the current study.

Family social support and respite services. Numerous studies have linked social support to decreased stress, including for caregivers of children with ASD (e.g., Pottie & Ingram, 2008), ADHD (Baldwin et al., 1995), developmental delays (Baker et al., 2003), Tourette's disorder (Schoeder & Remer, 2007), and Traumatic Brain Injuries (Chronister & Chan, 2006). Social support has also been incorporated into many models of caregiver (Mash & Johnston, 1990; Ostberg & Hagekull, 2000; Webster-Stratton, 1990) and family (e.g., Boss, 2002; McCubbin & Patterson, 1983) stress, and has even been highlighted as a key determinant of parenting quality (Belsky, 1984). Interestingly, work conducted by Pottie and Ingram (2008) indicated that perceived support is more predictive of positive intervention outcomes over actual received support for caregivers of children with ASD (Pottie & Ingram, 2008; Pottie et al., 2009).

Caregivers raising children with FASD have indicated the importance of social support for families with children with FASD (Brown & Bednar, 2003; Brown et al., 2005; Huculak & McLennan, 2009). In particular, caregivers stated their appreciation for social support from other caregivers of children with FASD that allows them learn from each other's experiences in a non-judgmental environment (Brown et al., 2005; Huculak & McLennan, 2009). Little research has investigated the social support networks for families with children with FASD. Foster caregivers interviewed by Gardner (2000) reiterated social support as an important coping strategy. One caregiver talked about the importance of having a support system around her: "If I didn't have people to call up when I'm frustrated, or go to a friend's house for a while, I couldn't make it" (p. 255). Although Paley et al. (2006) did not measure social support, they investigated the predictors of caregiver stress and found family resources to contribute significantly. Family resources included basic needs (e.g., food and shelter), transportation, and medical care, but also social needs, such as support from family members and friends. The more resources families had at their disposal, the lower their levels of caregiver stress. Additionally, Pottie and Ingram (2008) found support seeking behaviours of caregivers of children with ASD helped to ameliorate caregivers' experiences of stress. More research is needed to investigate caregivers' support networks and support-seeking behaviours.

Respite service has been indicated as a key service for caregivers by several FASD researchers (e.g., Giunta & Streissguth, 1988). According to Jones (1999) respite services "can provide parents with the emotional and physical nurturing they may need to continue parenting an alcohol-affected child" (p. 83). Several qualitative studies have revealed the important benefits respite services reportedly provide to families (e.g., Brown et al., 2005; Shepard, O'Neil, Down, & Morris, 2012). However, few studies have used quantitative approaches to measure the effectiveness of respite services for families with children with FASD. Interestingly, in a recent mixed methods study, respite was reported in interviews to help alleviate stress, but these effects were not necessarily reflected by changes decreased levels of stress as measured by the PSI (McLennan, Doig, Rasmussen, Hutcheon, & Urichuk, 2012). The authors suggest this may suggest that respite programs, although providing caregivers with a sense of temporary relief, do not impact chronic stress patterns and a combination of interventions would be most beneficial.

Unfortunately, caregivers have reported limited access to and funding for respite services, despite it being a key need for caregivers (e.g., Brown et al., 2005; Sanders, 2008; Walls & Pei, 2013). Caregivers have indicated respite services can be restricted based on the diagnoses their child has or has not received (Doig, McLennan, & Urichuk, 2009; Watson et al., 2013). In the past, it has also been identified as a key service gap for caregivers in Alberta (Huculak & McLennan, 2009).

Family quality of life. The investigation and promotion of the psychological well-being of children and their families has received a great deal of attention in research and practice. Ultimately, the goal of family interventions is to increase the well-being and positive outcomes for children, families, and communities. Although health researchers have been investigated quality of life for over three decades (Wood-Dauphinee, 1999), it is only more recently that this construct has gained attention in the social sciences. Since this time, caregiver quality of life has been found to be linked to levels of caregiver stress (Lee, Hwang, Chen, & Chien, 2009; Wheeler, Skinner, & Bailey, 2008) and social support (Sgarbossa & Ford-Gilboe, 2004).

Family quality of life has emerged as an important outcome for interventions for families with children with disabilities (Davis & Gavidia-Payne, 2009). Family quality of life moves beyond individual family members to incorporate all family members, taking an ecological approach. Family quality of life is heightened when the needs of all family members are met and family members are able to participate in things that are of value to them (Park et al., 2003). Family quality of life has been highlighted as an important service outcome for families with children with FASD (Alberta Centre for Child, Family, and Community Research [ACCFCR], 2007).

FASD Interventions

Due to their diverse needs, children with FASD require support in many areas of their lives, including health, education, and social services. Despite this wide range of needed supports, research concerning the efficacy of intervention program is only in the beginning stages. However, the last five years have shown an increase in the development and testing of evidence-based interventions. In particular, several recent review articles have provided an overview of interventions in Alberta and internationally (ACCFCR, 2010; Bertrand, 2009;

Bohjanen et al., 2009; Chandrasena, Mukherjee, & Turk, 2009; Paley & O'Connor, 2009; Peadon, Rhys-Jones, Bower, & Elliott, 2009; Peadon et al., 2009; Premji, Serrett, Benzies, & Hayden, 2004). The majority of studies were quantitative and focused on child factors, such as pharmaceutical treatments, social skills training, and classroom interventions, although a few of the studies highlighted the importance of training, consultation, and respite care to promote healthy family environments (ACCFCR, 2010; Bertrand, 2009; Paley & O'Connor, 2009). Premji and colleagues (2004) conducted a review of evidence-based interventions for children and youth with FASD for the ACCFCR. Two studies showed evidence of effectiveness for helping children and youth with FASD with stimulant medications (see Oesterheld et al., 1998; Snyder, Nanson, Snyder, & Block, 1997) to manage ADHD symptoms, and one study used Cognitive Control Therapy to help children's functioning in the classroom (see Riley et al., 2003).

In 2009, Bohjanen conducted an additional literature review concerning evidence-based interventions that were not included in the Premji et al. (2004) review. Six studies were critically examined. Two were quasi-experimental studies (Belcher et al., 2005; O'Connor et al., 2006) and one was a case study (Padgett, Strickland, & Coles, 2006) that focused on the efficacy of three community-based intervention programs to help mothers who might be at risk for having a child with FASD (Belcher et al., 2005), helping children learned fire safety (Padgett et al., 2006), and the effects of a social skills training, support group, and Child Friendship Training for children's knowledge of social skills (O'Connor et al., 2006). In 2009, Bertrand also reviewed five studies to provide a brief overview of a general intervention framework developed for individuals with FASD. All interventions provided children with multidisciplinary assessments, and incorporated instruction and training for parents and caregivers about FASD, advocacy skills, and caregiver support, and focused on specific areas of deficit or risk (e.g., math skills, compliance, learning readiness, executive functioning and regulation, and peer interactions and communication). Two additional review articles by Paley and O'Connor (2009) and Chandrasena, Maukherjee, and Turk (2009) indicated interventions have largely focused on animal studies, educational strategies, pharmaceutical interventions, and case management.

One additional study investigated the effectiveness of the *Coaching Families* program and found through retrospect analysis that caregivers' level of stress and needs decreased over the course of the intervention (Leenaars, Denys, Henneveld, & Rasmussen, 2012). The *Coaching Families* program provides both individualized training and support for caregivers of children with FASD by pairing each family with a social worker who plays a mentorship role. One reportedly key part of the program is the strong relationships that are built between families and mentors, through which mentors provide support, education, and referrals to community agencies, along with advocacy.

From these reviews it is clear that there still is a need for rigorous intervention research on the usefulness of caregiver support, respite care, education on caregivers' quality of life, stress, and competence using robust research designs (Olson et al., 2011; Peadon et al., 2009). Of the recent review articles that have published regarding FASD interventions, only a few studies have measured the impact of parent or caregiver-focused interventions (i.e., Parent-Child Interaction Therapy, Families Moving Forward, and Parent-Child Assistance Program). Despite the few studies in the area of caregiver-focused interventions, the little available information has highlighted that parent interventions can produce positive, measurable outcomes for families with children with FASD. Several researchers have highlighted the importance of family functioning for positive child outcomes. For instance, Olson and colleagues (2009) provided an overview of several factors that are important for families with children with FASD, including caregiver sense of competence and stress. Olson and colleagues (2009; 2011), as well as Paley and O'Connor (2009), have indicated decreasing parenting stress, increasing caregiver sense of competence, and promoting effective parenting skills are critical components of caregiver interventions. Interventions that address caregiver stress and feelings of competence are essential for the overall wellbeing of families and caregiver-child interactions. Research on child-focused FASD interventions has increased during the last decade, but the lack of research on caregiver-focused FASD interventions presents a key gap in the literature. Group caregiver interventions, such as education and support groups, occur in Western Canada and little research has examined how and why such groups for caregivers are useful. This is particularly important because caregivers often experience barriers to successfully accessing supports from educational and health care systems (Brown, 2004). Understanding those stressors, as well as barriers, and providing additional supports when needed is important for promoting positive family outcomes for Albertan families. However, little research has examined these factors for caregivers' raising children with FASD.

Group interventions for caregivers. Group interventions, such as education and support groups, are a cost-effective way of providing support for caregivers. Group interventions have been found to be effective for decreasing caregiver stress (e.g., Bohjanen et al., 2009; Pisterman et al., 1992) and for increasing caregivers' sense of competence or self-esteem (e.g., Bailey, 2007; Dunst, Trivette, & Hamby, 2007) for caregivers of children with disabilities, which promotes positive parenting practices and enhances caregiver-child interactions (Coleman & Karraker, 1998). These interventions are also particularly effective for increasing parent knowledge and reframing parenting attitudes (e.g., Kaminski, Valle, Filene, & Boyle, 2008). Group interventions provide support and encouragement from peers that promote a greater feeling of competence when coping with difficult situations and the possibility of change, which leads to greater positive parenting practices, strategies, and behaviours (Coleman & Karraker, 1998). Providing additional supports to caregivers when needed is important for promoting positive family outcomes for families.

The existence of support groups for caregivers of children with FASD in Western Canada has grown in the past decade, yet little research has been conducted to investigate the impact of group interventions for caregivers of children with FASD (see Porty, 2009). To bridge this gap, researchers interested in this field have investigated related literatures, including studies of caregivers of children with developmental disabilities, for guidance (Olson et al., 2011). Gradually, efficacious interventions are being identified. These additional perspectives are included below in the review of research concerning caregiver support groups and training.

Support groups. Several support groups or caregiver information sessions are held across Canada. For instance, several caregivers support groups have run successfully in Calgary, Alberta and Saskatchewan. Recently, a caregiver support group has begun in Edmonton, Alberta. However, previous attempts to create a support group over longer periods of time have been a challenge in Edmonton for the *Coaching Families* team (personal communication, 2010), a program run through *Catholic Social Services* aimed at providing support, advocacy, education, and referrals to caregivers of children with FASD. One suspected change in increased attendance of caregivers to the support group is the inclusion of educational workshops and support group discussions to the sessions. Several previous studies have highlighted the need or appreciation for support groups for caregivers (Brown & Bednar, 2003; Huculak & McLennan, 2009; McCarty et al., 1999).

A paucity of research has been conducted on support groups with caregivers with children with FASD. One unpublished Masters thesis has investigated the experiences of foster and adoptive caregivers of children with FASD participation in FASD support groups. Porty (2009) interviewed seven caregivers about the experiences participating in support groups for caregivers of children with FASD and to understand the strengths and limitations of support groups as an intervention. Caregivers appreciated the understanding, respect, and acceptance they found within the group, and appreciated the opportunity to speak about their experiences and to learn from others. Caregivers also spoke of feeling less isolated and felt they received mentorship, advocacy, education, and support at reframing their child's problem behaviours as symptoms of their disability. One possible negative impact of participating in the group included the creation of fear from hearing horror stories from other caregivers. Logistically, certain elements of the group were associated with increased evaluations of the groups' usefulness. These elements included having routine monthly meetings lead by a skilled facilitator, with members grouped by their child's age. Overall, caregivers clearly identified the benefits of support groups, and provided strong support for the continuation of this type of intervention.

Despite the lack of evidence found concerning support groups for caregivers with FASD, support groups have been shown to be beneficial for caregivers of children with ASD to increase caregivers' feelings of empowerment following their child's diagnosis (Banach, Iudice, Conway, & Couse, 2010). Additionally support groups have also helped new mothers with preterm babies to feel more self-efficacious about their parenting practices and behaviours (Liu, Chao, Huang, Wei, & Chien, 2010). In general, support groups have been found beneficial and helpful for caregivers of children with disabilities (e.g., Solomon, Pistrang, & Barker, 2001). Specifically, Yalom and Leszcz (2005) have outlined 11 interdependent factors that help facilitate the complex process of change in a support group setting. These factors include: (1) the instillation of hope; (2) the universality of experience; (3) imparting didactic information and direct advice; (4) altruistic behaviour; (5) the corrective recapitalization of the primary family group, and learning and changing dysfunctional patterns; (6) development of socialization techniques, and learning new ways to think or talk about a situation; (7) imitative behaviour, such as learning from watching others; (8) interpersonal learning about themselves and others from interactions in the group; (9) group cohesiveness and feeling apart of the group; (10) catharsis release of emotional tension; and (11) existential factors, and realities of life and death.

It is clear support group members will find some therapeutic factors more powerful than others. Yalom and Leszcz (2005) have suggested that hope is the most important factors for the effectiveness of support groups, because it is not only required for attendees continued participation, but hope in the process alone may be effective agent for change. The importance of hope as a factor of change has been reiterated by one study exploring caregivers' experiences of attending a camp for caregivers of children with FASD (Shepard et al., 2012). An analysis of caregivers' experience of attending the camp revealed several themes, such as acceptance and understanding as well as acquiring information and tools, which the researchers identified under the overarching theme, "Life Changing Experience: Providing Hope" (p. 79).

The rapid growth of parent support networks are a testament to the helpfulness of social support and support groups for families with children with FASD (Iverson, 2010; Wilton & Plane, 2006). The purposes of the current psychoeducational support group was to provide caregivers with necessary information and support, in order to help decrease caregiver stress, as well as increase their levels of self-efficacy, support, and quality of life.

Caregiver training and education. Caregiver training consists of programs in which caregivers are directly taught specific skills, ideas, and information. Caregiver training can take many forms, including face-to-face interactions, group sessions, telephone consultations, or video presentations. An underlying assumption of caregiver training programs is that caregivers can act as active agent of children's behaviour change, as the parent-child relationship bidirectionally shapes behaviour through social learning (Kaminski et al., 2008). Caregiver training programs have been found to help caregivers increase caregiver sense of competence (e.g., Hautmann et al., 2009), decrease stress (e.g., Pisterman et al., 1992; Singer et al., 2007), and increased social support (e.g., Marcynyszyn, Maher, & Corwin, 2011), as well as decrease children's feelings of anxiety (e.g., Khanna & Kendall, 2009), hyperactive behaviour (e.g., Fabiano et al., 2009), and negative parent-child interactions (e.g., McIntyre, 2008).

Caregiver training models have found the most empirical support for the treatment of young children's oppositional, noncompliant, and aggressive behaviours, and the promotion of social and emotional competence (e.g., Shriver & Allen, 2008; Webster-Stratton & Herman, 2010). For instance, the Incredible Years program (Webster-Stratton, 1992) has been consistently identified as an empirically-supported caregiver training program (Shriver & Allen, 2010). The basic level of the Incredible Years program uses a video presentation format with caregiver groups. Facilitated by practitioners, caregivers discuss the applicability of the presented examples. The Incredible Years program has been shown to be effective to help reduce oppositional, aggressive, and internalizing behaviours of young children, as indicated in several randomized control trials (see Webster-Stratton & Reid, 2003).

Caregiver training and education was indicated by caregivers of children with FASD as helpful to better understand FASD and associated cognitive, behavioural, and social deficits, which allows them to feel more competent as caregivers (Sanders, 2008). Caregivers indicated they must learn about FASD, including behavioural management strategies, in order to be effective caregivers of their children (Brown & Bednar, 2003; Brown et al., 2005; Brown et al., 2007; McCarty et al., 1999).

Mixed Methods Studies

Mixed methodology has been defined by Tashakkori and Creswell (2007) as "research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry" (p. 4). The inclusion of both quantitative and qualitative data sources has been advocated for over three decades (e.g., Cronbach, 1975; Denzin, 1978) and has substantially increased in popularity over the last decade (Leech & Onwuegbuzie, 2011). It is emerging as a methodology in school psychology because it can provide richer data and lead to a greater understanding of the studied phenomenon (Powell, Mihalas, Onwuegbuzie, Suldo, & Daley, 2008).

Several researchers have called for an increase in mixed methods work in order to understand child development and ecological family processes (e.g., Plano Clark et al., 2008; Turner & Johnson, 2010). Particularly in the area of family adaptation and stress, Turner and Johnson (2010) have called for an increase in mixed methods research to better understand family functioning. At the present time, few studies published in peer review journals have investigated family research with families with children with FASD using mixed methods (e.g., McCarty et al., 1999; Mukherjee et al., 2013). For example, one recent presentation at a health conference in northern Ontario focused on a study of families experiences of raising a child with FASD from a mixed method perspective using interviews and measures of stress, support, and hope (Watson & Radford-Paz, 2010). Additionally, McLennan and colleagues (2012) more recently evaluated a respite program for caregivers of children with FASD using both interviews and a parenting stress measure. Although an increased number of mixed methods studies in FASD research is beginning to emerge, few if any studies have investigated caregiver psychoeducational or support groups using mixed methodology. Mixed methods research is important as a single data set is often not sufficient to address the proposed research questions, as qualitative (or quantitative) data collection, analysis, and interpretation can be enhanced and augmented by the collection of secondary data (e.g., Creswell & Plano Clark, 2011), particularly when participants are experiencing high levels of stress and engaging in time-intensive research studies is difficult. Several calls have been made for ecological approaches to FASD intervention to promote positive child outcomes, such as supporting positive and consistent parenting practices and stable home environments (e.g., Olson, O’Connor, & Fitzgerald, 2001; Premji et al., 2004). The study addressed this gap by focusing on ameliorating risk factors and increasing protective factors for families by examining the impact of a psychoeducational support group for caregivers of children with FASD using mixed methods.

The Aim of the Present Study

The primary aim of this mixed methods study was to explore the impact of a *psychoeducational support group* for adoptive and kinship caregivers of a child with FASD involving (a) *psychoeducational* information that will be conveyed through structured discussions and presentations, and (b) *support* provided through open discussions of caregivers’ experiences. A variant of the embedded mixed methods design was used to explore caregivers’ experiences of the intervention and any possible change caregivers’ experienced related to the intervention (for a typical embedded design see Victor, Ross, & Axford, 2004). The design used was a variant because of the emphasis on participants’ experience of the intervention captured by the quantitative strand and enhanced and augmented by the collection of the qualitative strand (e.g., Creswell & Plano Clark, 2011; Luck, Jackson, & Usher, 2006). In this design, qualitative information was embedded into a quantitative framework that employed pre- and post-intervention measures.

Research questions. The study addressed the following mixed method research question: *What are caregivers' experiences of participating in the psychoeducational support group and how are these experiences related to caregivers' levels of stress, sense of competence, support, and quality of life?* Three research questions were addressed to answer this overarching question:

A. To what extent are caregivers' levels of stress, sense of competence, support, and quality of life altered by participating in the psychoeducational support group?

B. What are caregivers' individual experiences as a participant in the psychoeducational support group? In particular, what are the aspects of the psychoeducational support group are reported by caregivers' to be benefits and barriers?

C. What are the similarities and differences of caregivers' experiences of participating in the psychoeducational support group when compared across individual case studies?

CHAPTER THREE

Method

This chapter provides an overview of the methodology used in the current study. The chapter first provides an overview of the mixed methods design as well as the intervention setting of the psychoeducational support group conducted by the *Coaching Families* program. Second, how participants were recruited and the demographics of each participant are presented, followed by the data collection procedures and data sources for both quantitative and qualitative strands. Fourth, the types of data analysis used for the study is explained. Next, a description of how and when the quantitative and qualitative strands are integrated is outlined. Finally, an overview of issues of methodological rigor is explored.

Mixed Methods Design

An *embedded mixed methods design* was used because a single data set was not sufficient to answer the mixed method research question of examining the experiences of caregivers' participating in the intervention. An embedded mixed method design occurs when both qualitative and quantitative data are collected simultaneously, but one strand is embedded within the other (Creswell & Plano Clark, 2011). In this study, a qualitative strand was added to a quantitative strand for the purposes of better understanding the studied phenomenon of caregivers' experiences of participating in a psychoeducational support group using a CBRE approach (an annotation for this mixed methods design is *QUAN (qual)* = better understanding; Creswell & Plano Clark, 2011; see Figure 2). Quantitative data was enhanced and augmented by the collection of secondary qualitative data (e.g., Creswell & Plano Clark, 2011), meaning both strands improved and strengthened the understanding of each case (see Greene, Caracelli, & Graham, 1989 for a discussion of the *complementary* purpose for mixed methods). Using both

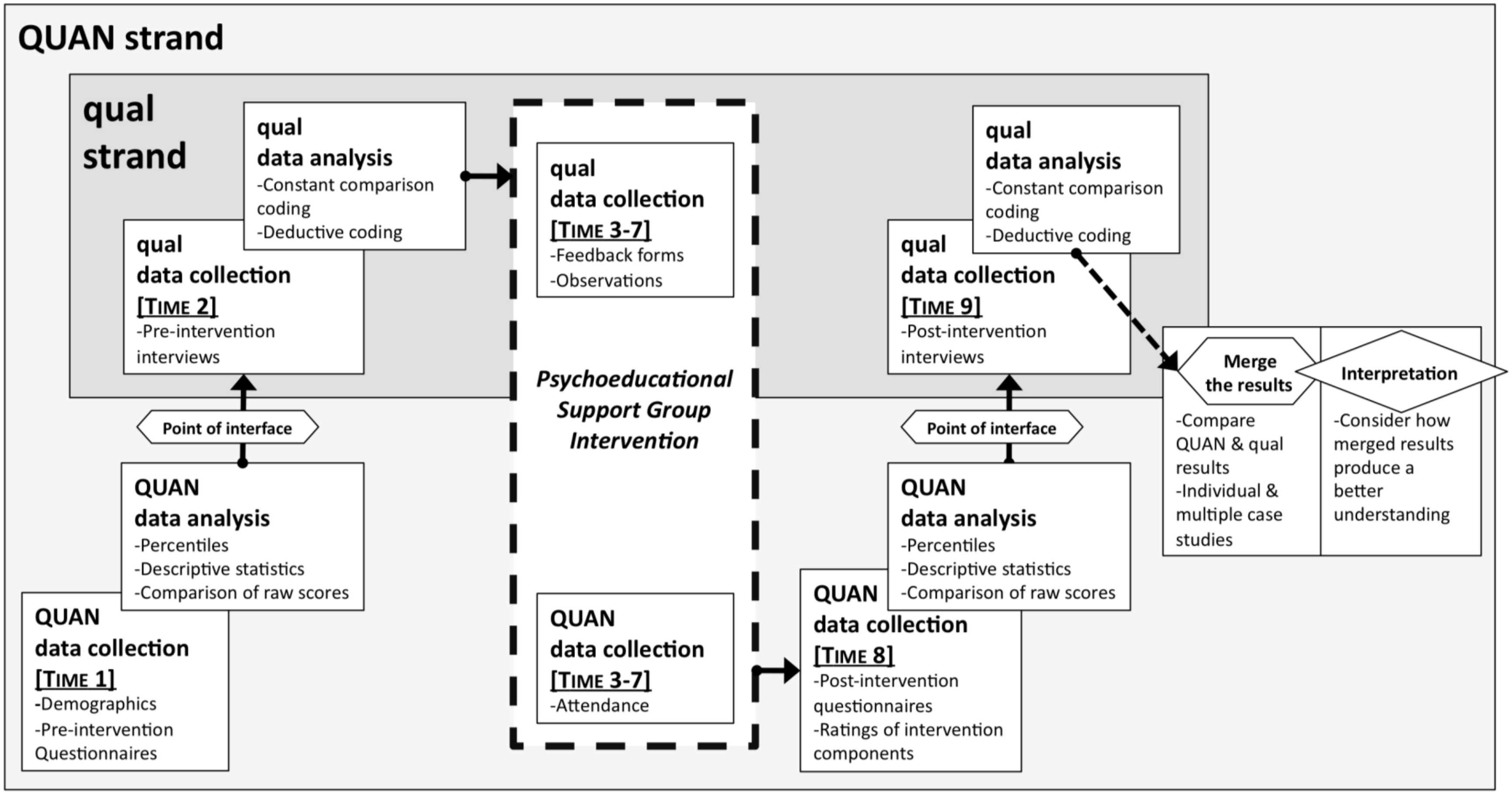

Figure 2. A embedded concurrent mixed method design, QUAN (qual) = better understanding, adapted from Creswell and Plano Clark (2011).

quantitative and qualitative data collection procedures, the current study took an individual case study approach to answer Research Questions A and B, and a multiple case study approach to answer Research Question C. Research Question B built upon information gathered in Research Question A. As Greene and colleagues (1989) indicated, a mixed methods approach is beneficial because "qualitative and quantitative methods are used to measure overlapping but also different facets of a phenomenon, yielding an enriched, elaborated understanding of that phenomenon" (p. 258). It allows for both emergent and predetermined methods that can include both open- and closed-ended questions using multiple forms of qualitative and quantitative methods (Creswell, 2003). Combining psychometrically sound questionnaire data with qualitative interview data is not a new approach within psychological practice. In fact, Powell, Mihalas, Onwueguzie, Suldo, and Daley (2008) indicated in the practice of school psychology, "by definition, assessment, whether for purposes of program planning or treatment, necessitates the consideration of multiple sources of data" (p. 293).

Intervention Setting

Coaching Families is a Catholic Social Services program in Edmonton, Alberta. It aims to help biological parents, step-parents, grandparents, kinship parents, foster, or adoptive parents to learn about and respond to the needs of their children who are affected by or strongly suspected of being affected by FASD. In the *Coaching Families* program, families are paired with a mentor that helps families to learn more about FASD, navigate systems, or act as an advocate on their behalf. The goals of the program are to build on family strengths and connect families to support in the community, help the families to deal with stressors and be more safe and stable environment, provide families with tools to decrease the risk of adverse outcomes, and to also raise awareness of FASD in the community (Catholic Social Services, 2013; Goetze, 2013).

Coaching Families began running a support group with information sessions in September 2011. Members of the *Coaching Families* team created and facilitated the intervention. Two *Coaching Families* team members (i.e., social workers and mentors in the *Coaching Families* program) co-facilitated the sessions. One facilitator was a seasoned mentor and the other facilitator had recently joined the team. Both facilitators were supervised by Sharon Schultz (Program Supervisor of *Coaching Families* and *Step by Step* Programs). The intervention consisted of five three-hour monthly sessions that included a range of both *psychoeducational* (i.e., providing information and reframing ideas of parenthood) and *support* (i.e., discussions of difficulties with other caregivers in a supportive environment) components at each session (see Appendix B for an overview of the intervention, along with a concise program logic model). Overall, the sessions included: (a) conversation between participants with food and refreshments (10 minutes); (b) introductions of facilitators and overview of current week (5 minutes); (c) introductions of participants and quick updates (15 minutes); (d) open discussions (60 minutes); break with food (10 minutes); (e) information sessions with semi-structured discussions (60 to 90 minutes); and (f) wrap-up and debrief (i.e., ending with one positive thing; 10 minutes). Information sessions included: FASD and youth justice; self-care and massages; and the Alberta Caregivers Association. One session consisted of a three-hour open discussion and the final session included an end-of-the-year luncheon. Previous information sessions have included: "FASD 101", an introductory information session on FASD held by a program coordinator of the Edmonton Fetal Alcohol Network, and information on respite programs in Edmonton. Several participants in the current study attended these previous sessions. Sessions were held on a weekday morning, as participants indicated this was the best time they could secure childcare (e.g., school, daycare).

The study was reviewed for its adherence to the ethical guidelines and approved by the Research Ethics Board at the University of Alberta. The researcher signed an oath of confidentiality for the purposes of working with *Coaching Families* and attending support group meetings. Informed consent was obtained from each participant involved in the project (see Appendix C for the Information Letter and Appendix D for the Consent Form). Pseudonyms were used whenever discussing data collection and results. Confidentiality was ensured as much as possible in the context of the group intervention.

Participants

Sampling. According to Stake (2006), cases chosen for multiple case studies should not only be relevant to the *quintain* (i.e., the object or phenomenon being studied), but also possessed similarities and differences in order to provide opportunities to learn about the complexity of the phenomenon across cases. Accordingly, purposeful sampling was employed in order to promote maximum learning (Merriam, 2009). Maximum variation sampling was the type of purposeful sampling used. Maximum variation sampling incorporates both unique and typical cases, that may illustrate a wide range of characteristics and experiences, in order to broaden our understanding of the phenomena (Glaser & Strauss, 1967; Merriam, 2009). Such characteristics included adoptive or kinship caregivers, length of time caregiving for a child with FASD, developmental stage of their child with FASD, involvement in other FASD interventions, and level of caregiver stress.

Recruitment and selection. Participants were recruited for this study through an existing *Coaching Families* support group (see Appendix E for a recruitment letter that was emailed to participants by the facilitator of the group). Identical samples were used, meaning the same participants were involved in qualitative and quantitative strands of the study (Onwuegbuzie & Collins, 2007). The target participants for the intervention were six adoptive or kinship caregivers of children between the ages of five and 16 years who are diagnosed or suspected of having FASD. Six caregivers were asked to participate in the psychoeducational support group, and three caregivers were selected for inclusion in the multiple case study. There are several reasons for the inclusion of only three caregivers. First, six to eight participants within a support group is recommended (Yalom & Leszcz, 2005), while caregiver education groups may be larger (Shriver & Allen, 2010). The inclusion of approximately six caregivers is important to help facilitate the supportive environment of the intervention and to promote group interactions (Yalom & Leszcz, 2005). Second, the inclusion of three caregivers, rather than all of the caregivers participating in the intervention, enhanced the confidentiality of caregivers' information. If all caregivers of the group had been selected for participation in multiple case study, confidentiality of participant information would be compromised. Third, due to the high levels of stress experienced by primary caregivers of children with FASD, it was expected that at least one participant would drop out over the course of the intervention, however this was not the case. Selected cases were chosen based of the number of completed points of data collection (i.e., interviews, questionnaires, and feedback forms), attendance at psychoeducational support group meetings, and the opportunities for maximum variation and learning. Four, it was determined that including three, rather than six, research participants was more appropriate based on the feasibility of the project timeline. Informed consent was obtained from each participant involved in the project (see Appendix C for the information letter and Appendix D for the consent form).

Adoptive and kinship caregivers were recruited because previous support groups with primary caregivers have held sessions for biological and non-biological caregivers separately, due to possible differences in experiences of these two groups (Porty, 2009). Non-biological caregivers often feel anger and resentment, whereas many birth parents may experience feelings of regret and depression (Sanders, 2008), and thus different groups may best serve their needs. Foster parents may also require alternate services to address the particular stressor they face. Furthermore, historically biological caregivers have not attended the *Coaching Families* support group. Therefore, the current study limited the recruitment of participants to adoptive and kinship caregivers in order to best suit their needs.

Demographics. All participants in the present study were female. The three participants had participated in at least seven out of nine points of data collection (described below). Participants vary in age: between 21 and 30, between 31 and 40, and between 41 and 50 years old. Participants self-identified their ethnic or cultural origin to be Canadian, Irish/German, and English. One participant had four children and two participants had one child. Two participants had children who were approximately 8-years-old and one participant had a child who was 14-years-old. Two children had been formally diagnosed with FASD and one child had been formally diagnosed with FAE. One child had been additionally diagnosed with ADHD. Two participants were married and one participant was single. Two participants indicated their highest level of obtained education was college or trade school, and the third participant indicated her highest level of obtained education was graduate or professional education. The household income of the participants varied between \$20000 to \$39999, and more than \$80000. All were currently participating in the *Coaching Families* program. Other professionals, services, or interventions that the participants and their child had been involved with in some capacity included psychologists, speech and language pathologists, social workers, occupational therapists, psychiatrists, dieticians, youth workers, teaching/educational assistants, Family and Children Services, Catholic Social Services, and respite services. See Table 1 for an overview of participant demographics.

Table 1

Demographic information of participants.

Pseudonym	Caregiver Type	Age Range	Relationship Status	Ethnic/ Cultural Origin (Self-Identified)	Child's age	Number of Years in Participant's Care	Child's Diagnosis/ Diagnoses
Jasmine	Adoptive	31-40	Married	Canadian	14	9	FAE
Terry	Adoptive	41-50	Married	Irish/German	8	1 or less	FASD, ADHD
Janelle	Kinship	21-30	Single	English	8	3	FASD, PTSD, Attachment Disorder

Data Collection Procedures

Quantitative and qualitative data were collected over nine time points. See Figure 2 for an overview of the data collected at each time point. Table 2 shows what data collection approaches and procedures were used to answer each research questions. See Table 3 for a timeline of the project. The quantitative strand grounded the larger embedded mixed methods study. Quantitative and qualitative data were compared and used to inform recommendations for future workshops for caregivers of children with FASD. More detailed information regarding the quantitative and qualitative strands is provided below. For the quantitative strand, questionnaires were administered before and after the intervention (Time 1 and 8), and attendance was recorded

Table 2

Connecting research questions, case study approach, strand, data sources, and analysis.

Research Questions	Procedure	Strand	Data Sources	Analysis
Overarching Research Question: What are caregivers' experiences of participating in the psychoeducational support group and its impact related to stress, sense of competence, support, and quality of life? (QUAN & qual)				
A. To what extent are caregivers' levels of stress, sense of competence, support, and quality of life altered by participating in the psychoeducational support group?	Individual case studies	QUAN & qual (mixed)	• Questionnaires (PSI/SF; CFS; PSOC; FSS; FQOL) • Ratings of intervention components • Interviews	Descriptive statistics Deductive analysis
B. In particular, what are the aspects of the psychoeducational support group are reported by caregivers' to be benefits and barriers? • Supplements research question A	Individual case studies	qual & QUAN (mixed)	• Interviews • Observations • Feedback forms • Ratings of intervention components	Constant comparison to create themes
C. What are the similarities and differences of caregivers' experiences of participating in the psychoeducational support group when compared across individual case studies? • Compares research questions A and B for a multiple case study	Multiple case study	QUAN & qual (mixed)	• Questionnaires (PSI/SF; CFS; PSOC; FSS; FQOL) • Interviews • Observations • Feedback forms • Ratings of intervention components	Cross-case analysis (across individual case studies of research questions A and B)

Table 3

Summary of research timeline.

	October	**November**	**December**
2011	Ethics Application	Participant recruitment	Participant recruitment **TIME 1: QUAN** • Questionnaires (demographics, PSI/SF, CFS, PSOC, FSS, FQOL)
2012	**January**	**February**	**March**
		Psychoeducational Support Group	
	TIME 2: qual • Interviews Transcription, coding, & analysis	**TIME 3: QUAN & qual** • Observations • Feedback forms • Attendance tally Transcription, coding, & analysis	**TIME 4: QUAN & qual** • Observations • Feedback forms • Attendance tally Transcription, coding, & analysis
	April	**May**	**June**
	Psychoeducational Support Group		
	TIME 5: QUAN & qual • Observations • Feedback forms • Attendance tally Transcription, coding, & analysis	**TIME 6: QUAN & qual** • Observations • Feedback forms • Attendance tally Transcription, coding, & analysis	**TIME 7: QUAN & qual** • Observations • Feedback forms • Attendance tally Transcription, coding, & analysis
	July	**August**	**September**
	TIME 8: QUAN • Questionnaires (demographics, PSI/SF, CFS, PSOC, FSS, FQOL) Transcription, coding, & analysis	**TIME 9: qual** • Interviews Transcription, coding, & analysis	Transcription, coding, & analysis

at each session (Times 3 to 8). Pre- and post-intervention questionnaire data (Time 1 and 8) helped to guide both pre- and post-intervention interview questions (Time 2 and 9). Comparisons of descriptive information (i.e., percentiles and mean raw scores) were made for two purposes:

(1) across time points for individual case studies (to address research questions A and B) and (2) compared across cases for the multiple case study (to address research question C). For the qualitative strand, data was collected pre-, during, and post-intervention. Interviews were collected pre- and post-intervention (Time 2 and 9). Pre-intervention interviews were collected to better understand caregivers' experiences of raising a child with FASD and how the intervention could best serve caregivers' needs. Post-intervention interviews were collected to understand caregivers' experiences of participating in the psychoeducational support group and to measure immediate change in caregivers' levels of stress, parental efficacy, support, and quality of life. Feedback forms and observations were collected at each of the five intervention sessions (Time 3 to 7). Observations and reflective notes were collected each session. Feedback forms were written by participants and consulted after the completion of the intervention and compared to the primary researchers' observational field notes.

A case study is the investigation of a bounded system, which allows for an in-depth, holistic approach to description and analysis by examining the particularity and complexities of a case (e.g., Merriam, 2009; Miles & Huberman, 1994; Stake, 1995). It can help to describe the implementation and evaluation of an intervention within a real-life context. As Stake (2005) attested, "case study is not a methodological choice, but a choice of what is to be studied" (p. 443). Case study research has been defined by Yin (2009) as "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident" (p. 18). The case approach is ideal for the collection of detailed data towards the purpose of embedded methodology and of the relationship between constructs (Yin, 2009), such as caregivers' experiences of the intervention and the relationship of their experiences with the constructs of stress, sense of competence, support, and quality of life. Multiple data sources were used to understand caregivers' experiences and to answer the research questions.

Stake (1995) and Yin (2009), both prominent case study researchers, have emphasized the pragmatic nature of case study research, which fits with the mixed methodological approach of the current study. Stake (2005) stated "as a form of research, case study is defined by interest in an individual case, not by the methods of inquiry used" (p. 443). Stake (1995; 2005) has outlined three types of cases: intrinsic, instrumental, and multiple case study. The present study focused on an *instrumental* multiple case study. An instrumental case is the examination of a case in order to provide insight into an issue (Stake, 1995). A multiple case study is a variant of a case study approach that includes two or more investigations of the same phenomenon or quintain (Santos, & Eisenhardt, 2004), which allows for an understanding of the similarities and differences between cases (Yin, 2009). The current study will examine the factors that contribute both positively and negatively to caregivers' participation in the psychoeducational support group, which will be investigated in order to help the development and implementation of future groups for caregivers of children with FASD.

Stake (1995) has also emphasized the importance of defining the boundaries of a case. Using Stake's (2006) approach to case study research, multiple case studies are the study of a quintain. The current study investigated the quintain of caregivers' experiences of participating in a psychoeducational support group, and therefore, the strands of current study took a multiple case approach (Yin, 2009). Multiple case studies is a common strategy for enhancing the transferability or naturalistic generalizations that can be made (Merriam, 2009; Yin, 2009). Miles and Huberman (1994) specified the key advantage of examining multiple case studies over single case studies:

> By looking at a range of similar and contrasting cases, we can understand a single-case finding, grounding it by specifying *how* and *where* and, if possible, *why* it carries on as it does. We can strengthen the precision, the validity, and the stability of the findings. (p. 29, emphasis in original)

For the current study, multiple data sources were collected over multiple cases, which enhanced the depth of our understanding of caregivers' experiences.

The multiple case study was bound in two ways. First, adoptive and kinship caregivers' experiences of participating in the psychoeducational support group were explored using individual case studies in order to understand how individual caregivers experience the intervention (Research Questions A and B). An overview of each research question with associated data collection strategies and analysis can be found in Table 2. Six caregivers were recruited for the psychoeducational support group research study. Six caregivers participated, and of these six caregivers three were selected for individual case studies (see Participant section above). Second, adoptive and kinship caregivers' experiences of the psychoeducational support group were compared across the multiple cases using a multiple case study approach to highlight similarities and differences in experiences of participating in the group (Research Question C; see Figure 3 for a visual representation of the overall case).

The multiple case study was an *embedded* multiple case study. An embedded case study occurs when different units of analysis are used to understand each case (see Yin, 2009, p. 50). An embedded multiple case design approach is regarded as being more robust as it allows evidence to be gathered from multiple perspectives, which can help to determine similar or contrasting results (Yin, 2009). The qualitative strand information was embedded and integrated with the case study information to provide a more comprehensive understanding. It maximized what could be learned about caregivers’ experiences, which is important when designing a case study (Stake, 1995). Interviews, observations, and document reviews were used, which have been outlined as appropriate data collection strategies for studying educational and intervention programs using case study research (Stake, 1995; Yin, 2009).

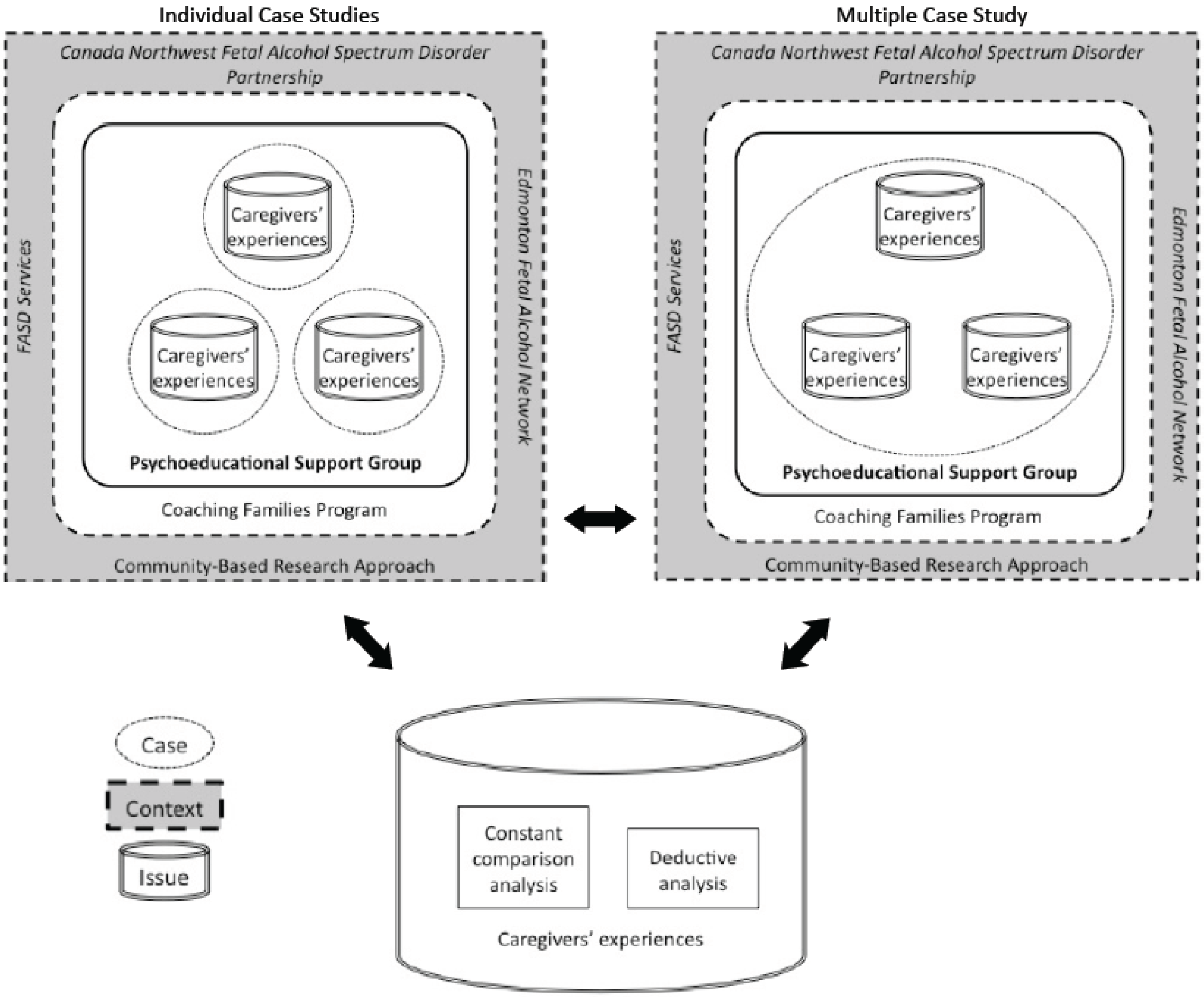

Figure 3. Individual and multiple case studies.

Data Sources

Quantitative measures. Pre-intervention quantitative measures included: demographics questionnaire; Parenting Stress Index/Short Form (PSI-SF, Abidin, 1995); FASD Family Stress Scale, used by Coaching Families (CFS Catholic Social Services, 2002); Parenting Sense of Competence Scale (PSOC, Johnson & Mash, 1989); Family Support Scale (FSS, Dunst, Trivette, & Jenkins, 2007); and Family Quality of Life Scale (FQOL, Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Post-intervention measures included: PSI/SF, CFS, PSOC, FSS, and FQOL, and ratings of components of the intervention. The demographics questionnaire and rating scale for components of the intervention were developed for the study (see Appendices F and G, respectively). Caregivers’ were be asked to complete a rating scale of various components of the group following the completion of the intervention to help determine what aspects the caregivers’ found helpful or useful (i.e., content areas covered, modes of presentation). Caregiver attendance to each session was also recorded. Additional information regarding the remaining quantitative measures is presented below.

Caregiver stress. Two measures were used to measure family stress: the PSI/SF and the CFS. The PSI/SF is a 36-item measure of caregiver stress that is an abbreviated version of the Parenting Stress Inventory (PSI/SF; Abidin, 1995), which is a reliable and well-validated measure. The PSI/SF is for caregivers of children up to 12 years of age and can be administered in less than 10 minutes. Three factors compose the PSI/SF (Parental Distress, Parent-Child Dysfunctional Interactions, and Difficult Child) and comprise the Total Stress score. The scale also includes a defensive responding scale to rate the validity of response patterns. Caregivers rate statements related to these factors on a five-point Likert scale from strongly agree (1) to strongly disagree (5).

Both the PSI/SF (e.g., Watson & Radford-Paz, 2010) and the PSI (e.g., Paley et al., 2005; Paley et al., 2006) have often been used to measure parenting stress in family research. Abidin (1995) has reported high internal consistency ($\alpha = .87$ for Parenting Distress, $\alpha = .80$ for Parent-Child Dysfunctional Interactions, $\alpha = .85$ for Difficult Child, and $\alpha = .91$ for Total Stress) and test-retest reliability ($r = .85$ for Parenting Distress, $r = .68$ for Parent-Child Dysfunctional Interactions, $r = .78$ for Difficult Child, and $r = .84$ for Total Stress) estimates for the PSI/SF. Both test-retest (r = .84) and internal consistency estimates are reported as strong for the PSI/SF.

The PSI and the PSI/SF Total Stress scores are highly correlated ($r = .94$, Abidin, 1995; $r = .87$, Haskett, Ahern, Ward, & Allaire, 2006). The validity of the PSI/SF has been supported by its comparison with the PSI, with each domain being highly correlated ($r = .92$ for Parenting Distress, $r = .73$ for Parent-Child Dysfunctional Interactions, $r = .87$ for Difficult Child; Abidin, 1995). The PSI/SF has been used in numerous studies with parents of children with various disabilities and health concerns (e.g., Smith, Oliver, & Innocenti, 2001; Tomanik et al., 2004), which have highlighted the relationships between stress, child behaviours, and support. Additionally, several studies have demonstrated the convergent, discriminate, and predictive validity of the PSI/SF (e.g., Haskett et al., 2006; Reitman, Currier, & Stickle, 2002), although the validity of the PSI/SF is continually being established.

The CFS (Catholic Social Services, 2002) is a 16-item measure of parental stress. The Coaching Families team developed the CFS, which covers many topics such as parental emotional and physical health, hope, resources, and finances. Parents respond to such questions as "I feel frustrated with the school system" and "I feel hopeless about our situation" on a five-point Likert scale from never (0) to constantly (4). The scale has been used in previous research evaluating the Coaching Families program (Leenaars et al., 2012). See Appendix H for a copy of the CFS.

Caregiver sense of competence. The PSOC is a 17-item, questionnaire that is one of the most common measures for assessing caregiver self-efficacy (Jones & Prinz, 2005). Johnson and Mash (1989) adapted the measure from the original scale developed by Gibaud-Wallston and Wandersman (1978, as cited in Johnson & Mash, 1989). Johnson and Mash (1989) validated the adapted scale using a normative sample of mothers and fathers, which revealed two factors: Efficacy and Satisfaction. An example of a question on the efficacy scale is "Being a parent is manageable, and problems are easily resolved." An example of a question on the satisfaction scale is "Being a parent makes me tense and anxious." Each item is answered on a six-point Likert scale from *strongly disagree* (1) to *strongly agree* (6). Seven items are reversely scored. Johnson and Mash (1989) reported an overall satisfactory internal consistency estimate (alpha level of .75), whereas Gibaud-Wallston and Wandersman (1978) report six-week test retest reliability estimates ranging from .46 to .82. A few researchers have demonstrated the scales convergent and divergent validity (Ohan, Leung, & Johnston, 2000; Rogers & Matthews, 2004) and Johnson and Mash (1989) reported a significant negative correlation between the PSOC and the Child Behaviour Checklist. See Appendix I for questions on the PSOC.

Family support. The FSS is an 18-item scale that assesses how helpful social support resources have been to caregivers' raising a child with a disability. Six factors were identified with 139 parents of children with developmental delays (Informal Kinship, Spouse-Partner Support, Social Organizations, Formal Kinship, and Professional Services, Dunst et al., 2007). Hanley and colleagues (1998) found internal consistency estimates to be acceptable to good (alphas range from .60 for Professional Services to .85 for Total score). The ACCFCR (2007) has also recommended the FSS for working with families with children with FASD. Each item is ranked on a five-point Likert scale from *not at all helpful* (1) to *extremely helpful* (5). *Not applicable* is also provided as an option (0). An example of a question on the FSS is "How helpful has each of the following been to you in terms of raising your child(ren)? E.g., parent group members."

Family quality of life. The FQOL scale is a 25-item measure that was piloted with 488 families. Five factors comprise the scale (Family Interaction, Parenting, Emotional Well-Being, Physical-Material Well-Being, and Disability-Related Support, Hoffman et al., 2006). Two examples of questions on the FQOL are: "My family enjoys spending time together" and "My family member with special needs has support to make progress at school." Questions are answered on a five-point scale from *very dissatisfied* (1) to *very satisfied* (5) with a middle anchor of *neither satisfied nor dissatisfied* (3). Internal consistency estimates of the scale are high (alpha levels range from .88 to .94, Hoffman et al., 2006). Convergent and divergent validity for the FQOL has been somewhat established with other measures of quality of life (Hoffman et al., 2006). Additionally, ACCFCR (2007), in collaboration with researchers and families, has recommended the FQOL for work with families with children with FASD.

Rating scale of intervention components. Caregivers were asked to rate components of the intervention after the five sessions of the intervention were completed (see Appendix G). The purpose of the rating scale was to better understand caregivers' experiences of the sessions and what they liked and found helpful. Several aspects of the intervention were covered in the rating scale. The rating scale currently consists of 38 close-ended and 10 open-ended questions. Closed-ended questions were answered on a five-point Likert scale. The Likert scales contained various anchors, depending on the content of the question. Caregivers were asked to provide their options regarding the psychoeducational support group in general (i.e., "Overall how would you rate the group", etc.), the psychoeducational component (i.e., "How satisfied were you with the amount of information that was presented", etc.), the support group component (i.e., "How understood did you feel in this group?", etc.), and information regarding specific sessions (i.e., "How helpful was [session 5]?", etc.). The 10 open-ended questions pertained to questions concerning the psychoeducational support group in general and suggestions for improvements. Caregivers were asked to provide information regarding what they liked most/least about the sessions, and what they found most helpful/least helpful about the sessions. The caregiver rating scale was adapted from Larsen, Attkisson, Hargreaver, and Nguyen's (1979) Client Satisfaction Questionnaire (CSQ-8), the SMART Fund Guide to Using Outcomes to Design and Manage Community Health Activities (Plan:Net Limited, Strathcona Research Group, Coyne, & Cox, n.d.), and Glosser and Wexler's (1985) evaluation form for an educational support group.

Attendance. Caregivers' attendance at the psychoeducational support group sessions was recorded. The purpose of recording caregivers' attendance was to shed light on what caregivers' find useful and valuable, provide a behavioural indicator of possible dissatisfaction with the intervention or high levels of caregiver stress, and help to form post-intervention interviews regarding caregivers' experience of the intervention.

Qualitative strategies. The qualitative strand included three sources of evidence: semi-structured interviews, feedback forms at the beginning of each intervention session, and observations. See Table 2 for research questions and associated data collection strategies. The proposed study also originally planned to include journal entries from caregivers written between sessions; however, it was decided that the time commitment of writing the journal entries would too great for participants and therefore was omitted.

Interviews. Semi structured interviews were conducted before and after the psychoeducational support group was completed. Face to face interviews were scheduled at a time and place convenient to the participant (i.e., either at participants' homes or at a *Catholic Social Services* office). Interviews conducted before and after the intervention were conducted in one session approximately 1.5 hours in length. The first interview with caregivers began by reviewing the purpose of the study and obtaining informed consent. Information related to the caregivers' background, demographic information, and general experiences of raising a child with FASD were also gathered during the first interview. See Appendix J for an example of the pre-intervention interview protocol and Appendix K for an example of the post-intervention interview protocol.

Interviews conducted prior to the commencement of the intervention were focused on exploring the needs of primary caregivers to gather information and inform the intervention. Questions regarding caregivers' levels of stress, sense of competence, social support, and quality of life were also explored. Interviews following the intervention focused on caregivers' experiences of participating in the intervention, and how participating in the intervention may affected their levels of stress, sense of competence, support, and quality of life. An interview protocol was used based on a list of primary and secondary topical questions (see Appendix L). Interviews were audio recorded and transcribed verbatim shortly after completion with pseudonyms and other identifying information removed from the data. The primary investigator transcribed the pre-intervention interviews and a transcriptionist transcribed the post-intervention interviews. All transcripts were reviewed by the primary investigator for accuracy.

Feedback forms. Short feedback forms were \ collected at the beginning of each psychoeducational support group session (see Appendix M). Feedback forms at the beginning of each session asked questions about how caregivers had been functioning since the last psychoeducational support group meeting, and determined what aspects of the last session were helpful or not helpful for caregivers. Caregivers were also asked to rate how the had been functioning, in general, on a 10 point Likert scale from very bad (1) to very good (10). Caregivers' anecdotes of experiences related to aspects of the session were encouraged.

Observations. The researcher observed the psychoeducational support group sessions. The role of the observer, based on Gold's (1958) typology, was dependent on the number of facilitators available to facilitate the psychoeducational support group. Two facilitators were present at every session and therefore the researcher acted as an *observer as participant*; completing the observations of the sessions took priority over participation or facilitation. Field notes during the sessions were recorded on an observation protocol. See Appendix N for an observational protocol based on information from Merriam (2009) and Yin (2009) and Appendix O for a completed example. Field notes included both descriptive and reflective notes (Yin, 2009). Additional notes were recorded following the end of each session. Field notes recording during and after each session used pseudonyms or participant number and any identifying information removed.

As Merriam outlined (2009), several factors can be the focus of an observation. For the purposes of the current study, observations focused on the participants, interactions and activities between participants, and any subtle factors, including critically examining "what does *not* happen" (Patton, 2002, p.295, emphasis in original). Critical incidents related to caregivers' experiences of the psychoeducational support group were also recorded. Observations were compared and discussed with the facilitators.

Data Analysis

Quantitative analysis. Descriptive analysis was completed for each pre- and post-intervention measure. For PSI/SF ratings, percentiles were calculated based on comparisons to normative data. For the remaining quantitative measures, raw scores for each pre- and post-intervention measure were used to create profile descriptions for each individual case, which was then used for multiple case study comparisons. For the CFS and Rating Scale, individual item ratings for each item were documented and reviewed for case conceptualizations. For scores derived from the PSOC, FSS, and FQOL, the average raw score for each subscale and total scores were provided for case conceptualizations. Mean raw scores for pre- and post-intervention ratings were also derived for these measures for pre- and post-intervention comparison for the PSI/SF, PSOC, FQOL, and FSS to provide information regarding each individual case. Profile descriptions for each participant are presented below based on the descriptive information. See Appendix P for raw scores, descriptive scores, and percentiles for each case.

Qualitative analysis. Qualitative data analysis began as the data (i.e., interviews, feedback forms, and observations) was collected. Preliminary reviews of the qualitative data occurred when transcribed. Line by line coding during the initial stages of the research project helps a researcher to begin to look at the data analytically (Charmaz, 1990). Computer assisted qualitative data analysis software, NVivo, was used for the purposes of data management and coding. Coding or memo notes were kept throughout the coding process. Qualitative data analysis of information gathered during or after the intervention focused on caregivers' experiences of the psychoeducational support group; however, analysis also focused on each participant's broader experience in order to better situate their experience of the group within context. Qualitative data analysis took two approaches: constant comparison and deductive analysis. Both constant comparison analyses and deductive analyses, based on predetermined concepts, were used for individual case studies for Research Questions A and B and cross case analysis for Research Question C for the multiple case study.

Individual case studies were created for Research Questions A and B. Individual case study data were first coded for Research Question B using the constant comparison method of inductive coding in order to explore emergent themes and ideas, and relationships between themes and ideas (e.g., Charmaz, 1990; Glaser & Strauss, 1967). The constant comparison method has been widely used for analyzing qualitative data. Interview, feedback forms, and observations qualitative data were coded using this method. Coding using the constant comparison method occurred in three iterative phases: (1) open coding of descriptive information; (2) analytical coding; and (3) the creation of categories or themes (Merriam, 2009). These phases resulted in three types of codes, outlined by Miles and Huberman (1994): descriptive, interpretive, and pattern codes. Open coding occurred in the beginning phase of data analysis and occurred by reading transcripts line by line and making notations regarding anything that may be relevant to the study's purpose. Grouping open codes into relevant groups is referred to as analytic coding and was completed during the second phase of data analysis. Finally, categories or themes were created based on grouping analytic codes. Categories are all supported by participant quotes below.

Following the constant comparison coding, deductive coding was conducted to gather information about caregivers' levels of stress, sense of competence, quality of life, and support before and after the intervention for Research Question A. Deductive coding was done using Braun and Clarke's (2006) approach to thematic analysis in order to understand the themes related to the "a priori" or "prefigured" categories (Crabtree & Miller, 1992; Creswell, 2013). Similar to constant comparison coding, thematic analysis was completed by generating initial codes, which are then collated into themes. Themes were reviewed and checked for consistency and redefined over time. Themes were created to better understand caregivers' experiences related to the a priori categories.

Cross-case analysis was conducted to create multiple case studies for Research Question C. Comparisons across individual case studies from Research Questions A and B were used to answer Research Question C. Cross-case analyses using data derived from constant comparison and deductive analysis methods were conducted in order to investigate the quintain (i.e., caregivers' experiences of participating in the psychoeducational support group). Cross-case analysis was used to understand both similarities and differences across cases. Using Stake's (2006) approach, individual case findings were merged to create tentative assertions about the multiple cases using matrices. Matrices were used to help generate themes across individual cases (see Discussion section below).

Qualitative dominant data analysis. As Dzurec and Abraham (1993) state, as cited by Onwuegbuzie and Leech (2005), "meaning is not a function of the type of data collected (i.e., quantitative vs. qualitative). Rather, meaning results from the interpretation of data, whether represented by numbers or by words" (p. 379). A central issue for mixed methods is how to create legitimate meaning from integrating by qualitative and quantitative data effectively (Plano Clark, Garrett, & Leslie-Pelecky, 2010). According to Onwuegbuzie and colleagues (2011), qualitative dominant crossover mixed analysis involves the mixed methods research taking a qualitative approach to analysis, with the belief that quantitative information will enhance the answer to the research question. As Greene (2007) highlights, theoretically crossover analysis is the process of "using aspects of the analytic framework of one methodological tradition in the analysis of data from another tradition" (p. 155). At the lowest level of integration, qualitative dominant crossover analysis involves combining descriptive quantitative information with one or more sets of qualitative data (Onwuegbuzie et al., 2011). Thus, despite being a quantitatively-focused embedded study, the analysis of the current project is categorized as qualitative dominant data analysis, since the analysis of quantitative data was restricted to descriptive statistics and comparison to normative samples, and did not include inferential statistics, which is a necessary element for quantitative dominant analysis (Onwuegbuzie et al., 2011; for an example of qualitative dominant analysis see McAuley, McCurry, Knapp, Beecham, & Sleed, 2006). Due to the very small sample size, inferential statistics were not appropriate for comparisons. For the current study, descriptive information of questionnaire data was used in the development of individual case analysis and cross-case analysis. Descriptive statistics and answers to particular items were used to help facilitate the collection of interviews.

Data Integration and Point of Interface

The current study included integration at all three levels of possible data integration or points of interface for mixed methods research described by Fetters, Curry, and Creswell (2013): design, methods, and interpretation or reporting. First, using a multiple case study approach, the initial point of interface occurred at the design phase. In order to create a comprehensive understanding of each case and to address the mixed methods research question, both qualitative and quantitative data was collected. Second, data was integrated at the methods level through *embedding*, with data collection and analysis being linked at multiple points (Fetters et al., 2013). Pre- and post-intervention quantitative data informed pre- and post-intervention interview questions, and constant comparison and deductive coding supported quantitative findings in both individual and multiple case studies. Third, data integration also occurred at the interpretation or reporting level through three different means: narrative, data comparison, and joint displays (Fetters et al., 2013).

Mixed methods researchers often mix qualitative and quantitative findings in the discussion section as another form of integration (Plano Clark et al., 2010). In the current study, mixing occurred both in the Findings and Discussion sections. Data integration occurred at the analysis phase, and described in the Findings section, with the data comparison of quantitative and qualitative data based on a priori factors, as well as *cross-case analysis* that has been used as analytic strategy to combine qualitative and quantitative data across multiple cases (Bazeley, 2009; Caracelli & Greene, 1993; Jang, McDougall, Dawn, Herbert, & Russell, 2008). Quantitative data, such as different levels of caregiver stress, helped to highlight important qualitative themes and to indicate which themes should be revisited in the context of the quantitative information. Individual case study analyses of both qualitative and quantitative data followed a similar approach to the multiple case study conducted by Frels and Onwuegbuzie (2013) who used a *qualitative-dominant crossover mixed approach*. Like Frels and Onwuegbuzie (2013), several data collection procedures were employed, but interviews represented the major data collection technique. In addition to interviews, both standardized and non-standardized questionnaires were given to participants to complete before and after the intervention. Comparing the quantitative scores with qualitative responses for each case involved data comparison and data integration for crossover analysis (Onwuegbuzie et al., 2010). Data comparison included comparing quantitative and qualitative data findings, and data integration included integrating quantitative and qualitative data and findings into a coherent whole. Joint displays, including matrices, were also used when interpreting and reporting the findings of the study, as they have been suggested by Plano Clark, Garrett, and Leslie-Pelecky (2010) to be helpful for integrating qualitative and quantitative information. Joint display matrices were used to display both qualitative and quantitative data in order for the two sources to be directly compared. Multiple case study matrices highlighted congruent and discrepant evidence for themes across data (Creswell & Plano Clark, 2011; Stake, 2006). Quantitative data was displayed in joint displays and compared to convergent and discrepant qualitative findings (for examples see Creswell & Plano Clark, 2011, p. 229-230).

Enhancing Methodological Rigour

Onwuegbuzie and Johnson (2006) suggested the techniques to enhance the validity of a mixed methods study should be used "at each stage of the mixed research process" (p. 56). Therefore, the following sections provide details regarding strategies used to enhance the validity of the quantitative strand and the trustworthiness of the qualitative strand, as well as inference quality and legitimation for the mixed methods study.

Validity and reliability. Validity can be defined as an account that accurately reflects features of the studied phenomenon that it is intending to describe or explain (Hammersley, 1987). Alternatively, reliability refers to the consistency of a measurement or inference. Due to possible threats for the current study, internal and construct validity, as well as reliability, was enhanced by using measures that have evidence of being valid and reliable for measuring caregiver constructs, such as caregiver stress and sense of competence. Additionally, ACCFCR (2007) has recommended specific measures to use measuring common outcomes for FASD interventions, based on recommendations from caregivers of children with FASD, policy makes, researchers, and service providers. These recommended measures include the FSS and the FQOL, which were used in this research study. Concerns of threats to external and statistical validity were less important for the current study because generalizations and statistical inferences are not be made.

Trustworthiness. For qualitative research, Lincoln and Guba (1985) suggested the use of the term *trustworthiness* over *validity* and separated trustworthiness into four categories: credibility, confirmability, dependability, and transferability (p. 300), each of which is discussed below. Several strategies were employed to enhance each aspect of trustworthiness.

Credibility. Credibility refers to how congruent the findings of a research study are with the data that has been collected (Merriam, 2009). Patton (2002) argued that credibility is ultimately related to purposefully looking for variation or alternative perspectives to understand the topic that is being studied. As Patton (2002) stated, researchers' must "look for data that support alternative explanations. Failure to find strong supporting evidence for alternative ways of presenting the data or contrary explanations helps increase confidence in the original, principle explanation you generated" (p. 553, emphasis in original). I purposefully looked for alternate explanations. Maximum variation sampling was used to the largest extent possible to help provide opportunities for alternative perspectives and understandings from caregivers. Negative or discrepant findings are also presented. An adequate amount of time collecting the data was spent in order for the data and emergent findings to become saturated and for alternative explanations to emerge. Lincoln and Guba (1985) outlined saturation as "redundancy, emergence of regularities in the data (a 'feeling of integration'), and overextension (excessive dross, a 'feeling of irrelevance')" (p. 265).

Several additional strategies were used to enhance the credibility of a study. Multiple data sources and methodological triangulation were used in order to compare and contrast information from different sources (Patton, 2002; Stake, 1995; Yin, 2009). Stake (1995) has defined methodological triangulation as investigating the same phenomenon using different methods, such as interviews, questionnaires, and observations, in order to increase confidence in the interpretations that have been made. Facilitators of the intervention met to discuss and compare collected data. Moreover, themes and categories were shared with caregiver participants through the process of member checking to determine if my interpretations were congruent with their own perspectives, to clarify any misunderstandings, and identify any potential bias (Lincoln & Guba, 1985). Appendix Q provides an example of themes shared with participants at an end-of-the-year barbeque. Additionally, I enlisted the help of a competent peer debriefer (Lincoln & Guba, 1985) and debriefed following each stage of the study to discuss insights and observations, and received feedback regarding the information. Debrief sessions were also reflected upon in the researcher's ongoing journal.

Finally, two things were completed to promote research reflexivity. Reflexivity refers to the "process of reflecting critically on the self as researcher, the 'human as instrument'" (Lincoln & Guba, 1985, p. 183). First, I have stated my bias upfront as much as possible regarding my experiences, assumptions, theoretical framework, and worldview, which can all affect the credibility of interpretations of the data. Second, I wrote journal reflections throughout the research process to critically reflect on my own bias, experiences, and challenges (see Appendix R for an example of an entry).

Dependability and confirmability. Lincoln and Guba (1985) advocated for the terms *dependability* for *reliability* and *confirmability* for *objectivity*. However, instead of emphasizing the replication, these terms refer to the consistency between the data collected and the inferences drawn. Lincoln and Guba (1985) suggested the use of an audit trail to describe the details of how and why decisions are made and how data is coded, included in the journal reflections (see

Appendix R). Coding memos also provide such information (see Appendix S). Both were employed in this study. Additionally, transcriptions of each interview were made of the interview data to minimize mistakes and misunderstandings during the coding process (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Finally, a peer knowledgeable of qualitative research methods was asked to complete a confirmability and dependability audit following the completion of the data analysis and integration stages (Lincoln & Guba, 1985). The independent auditor was asked to review the audit trail, data analysis documents, and written findings to assess the confirmability and dependability of the study, as well as the availability and completeness of the documents.

Transferability. Lincoln and Guba (1985) outlined that transferability occurs when findings are shown to have applicability in other contexts. Readers have the opportunity to assess the applicability by reading a thick description of the studied phenomenon. Thick description must be provided in order for the reader to have all the information necessary to understand the findings (Lincoln & Guba, 1985). Teddlie and Tashakorri (2003) also use the term *inference transferability* to denote external validity and transferability for mixed methods studies, and highlight several different types, such as *ecological transferability* for transferring to alternative contexts or settings. Additionally, Stake and Trumbull (1982) introduced the term *naturalistic generalizations* to denote the process of readers making generalizations from case studies based on the similarity of the contexts and participants between cases. In order to help readers make naturalistic generalizations, Stake and Trumbull (1982) suggest researchers must provide readers with vicarious experiences through personal descriptions and narratives.

The goal of the current study was to better understand the experiences of caregivers', and to provide insights for other community groups running group interventions for caregivers of children with FASD. For the current study, a thick description of the participants, setting, and findings with adequate evidence in the form of participant quotes are provided. A list of documents used for analysis, including interview and observation protocols, has been included to provide sufficient detail to readers regarding the study's procedures (see Appendix T). Maximum variation sampling were also used to provide a greater range of applicability for the readers of the study (Merriam, 2009).

Mixed methods legitimation. Both *inference quality* (Teddlie & Tashakorri, 2003) and *legitimation* (Onwuegbuzie & Johnson, 2006) are terms that have been used in reference to validity in mixed methods research. Teddlie and Tashakorri (2003) suggested inference quality be used as a term because it transcends both qualitative and quantitative research and inferences drawn from deductive and inductive methods. They further suggested inference quality can be separated into two important aspects of, *design quality* and *interpretive rigor*, that focus on the quality of inferences drawn from the mixed methods study. Design quality encompasses the evaluation standards for mixed methods research and can be examined through the qualitative and quantitative procedures used in the current study, as well as how each element has been integrated (Teddlie & Tashakorri, 2003). The procedures are presented above for the evaluation of these elements. Interpretive rigor refers to the accuracy or authenticity of the conclusions of the study (Teddlie & Tashakorri, 2003) and may be more closely associated with the traditional notion of validity.

The evaluation of inferences based on both qualitative and quantitative information in mixed methods studies has also been termed *legitimation* (Onwuegbuzie & Johnson, 2006). Onwuegbuzie and Johnson (2006) defined legitimation as "the difficulty in obtaining findings and/or making inferences that are credible, trustworthy, dependable, transferable, and/or confirmable” (p. 52). In order to enhance legitimation, Dellinger and Leech (2007) have developed a validation framework to help evaluate the validity, trustworthiness, and legitimation for mixed methods studies. As suggested by Dellinger and Leech (2007) this framework was used when designing and conducting the current mixed methods study, and when evaluating other mixed methods research in the area, with particular attention placed on the inferential consistency, utilization, and consequential element of the findings. The current study endeavored to achieve interpretative consistency by enhancing validity through the use of appropriate questionnaires, trustworthiness of the qualitative data collection procedures and analysis, and consistent links between research questions and the study design.

Four challenges described by Creswell and colleagues speak to threats to the validity of the current mixed methods study, and embedded studies in particular (Creswell, Plano Clark, & Garrett, 2008; Creswell & Plano Clark, 2011). First, integrating quantitative and qualitative strands is important for mixed methods research and it is important to evaluate whether the strands have been successfully integrated (Yin, 2006). Bazeley (2009) has suggested comparing quantitative and qualitative strands using a matrix or joint display to integrate data successfully, which were employed in the current study. Second, Creswell and Plano Clark (2011) highlighted the challenge related to the researchers’ lack of expertise with quantitative, qualitative, and mixed methods research. The researcher continued to address her lack of knowledge of qualitative data collection and analysis procedures by attending additional workshops, volunteering on qualitative research projects, and reading about mixed methods and qualitative methodologies. Third, Creswell and Plano Clark (2011) also suggested there is a possibility of introducing treatment bias in embedded mixed methods designs. Collecting unobtrusive data during the intervention helped minimize possible bias as a result of introducing data collection during the intervention (Victor et al., 2004). Additionally, rigour was enhanced by having a second coder, member checking, producing an audit trail, checking and rechecking the accuracy of the data, and continually acknowledging the biases of the researcher (Yin, 2010). Finally, Creswell and Plano Clark (2011) underscored the extensive time constraints a mixed method study can place on a researcher. Placing an emphasis on both quantitative and qualitative data collection extended the time it took to complete the project. Moreover, it took time to build trust with participants. The primary researcher attended the Coaching Families support group prior to the commencement of the study in order to build relationships with potential participants.

CHAPTER FOUR

Findings

Three women participated in the current study. Their lives are unique and distinct, with different ages, occupations, interests, and values. Despite their differences, each woman cares for a child who has been diagnosed with FASD and attended the Coaching Families psychoeducational support group. The participants’ interviews, psychoeducational support group feedback forms and observations, and participants’ questionnaires were analyzed and described through the creation of themes or codes. This chapter focused on providing a brief background of each case, the themes that reflect their individual experiences (including benefits and barriers, and related a priori factors), and a comparison of these themes across cases for a multiple case study, in order to answer the following three research subquestions:

A. To what extent are caregivers’ levels of stress, sense of competence, support, and quality of life altered by participating in the psychoeducational support group (i.e., individual case studies)?
B. What are caregivers’ individual experiences as a participant in the psychoeducational support group? In particular, what are the aspects of the psychoeducational support group are reported by caregivers’ to be benefits and barriers (i.e., individual case studies)?
C. What are the similarities and differences of caregivers’ experiences of participating in the psychoeducational support group when compared across individual case studies (i.e., multiple case study)?

This chapter begins with an introduction to each of the participants as they described their experiences and perspectives. Following the introduction, caregivers’ individual experiences are reviewed, including a review of their levels of stress, sense of competence, support, and quality of life that were altered by participating in the psychoeducational support group (i.e., individual case studies to address Research Question A), following what aspects that were found to be benefits and barriers (i.e., individual case studies to address Research Question B). This is followed by a review The chapter finished with a cross-case comparison of the benefits and barriers to participation, and impact on a priori factors, across individual cases (i.e., multiple case study to address Research Question C).

Background to Case Studies

Case one: Jasmine. Jasmine is a mother of four in her mid-forties who lives in a suburban, middle-class home in a large Canadian city. Jasmine works from home for a large financial institution. She enjoys her work, particularly because it provides some flexibility in her schedule. Jasmine is married. Her husband, Clarence, has not worked outside the home for the last few years in order to take care of their youngest child. At the time of the study, he was currently looking to return to work.

Jasmine and her husband have adopted four children: two boys and two girls. Jasmine reported that she always wanted to adopt children. Their oldest child is 14-years-old and their youngest child is two-years-old. They adopted their first child, Logan, when he was five-years-old, approximately nine years ago. When Logan was adopted, he already had a diagnosis of Fetal Alcohol Effects[3]. This diagnosis was disclosed to Jasmine and Clarence at the time of the adoption. Jasmine knew little information about the diagnosis, including what the process was or

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[3] Fetal Alcohol Effects (FAE) was a diagnosis provided to individuals who had some but not all of the characteristics of Fetal Alcohol Syndrome, which included growth deficiency, a pattern of dysmorphic facial features, and some manifestation of central nervous system dysfunction. The term FAE was criticized for being broadly used and poorly defined (Astley & Clarren, 2000), and has since been replaced by other terminology under the umbrella of FASD.

where it had occurred. See Figure 4 for a cursory overview of events from Jasmine's story, including when she adopted her son and began her involvement with the Coaching Families. Jasmine and Clarence adopted their second child approximately three years after they adopted Logan. Jasmine recounted that Logan really wanted Jasmine and Clarence to adopt another boy the same age as Logan. Despite these pleadings, Jasmine and Clarence adopted a baby girl after receiving a call from Alberta Human Services about the possible adoption. Jasmine indicated Logan was not particularly thrilled to have a new crying, baby sister at home. Following adopting their second child, they adopted another girl and a baby boy.

Jasmine and her husband, Clarence, have accessed or been involved with several services to help support their family and their son. The services or services providers they have been contact with include social workers, psychologists, occupational therapists, teaching assistants, and respite services. Jasmine and Clarence's family doctor suggested they take their son to a psychologist, the process of which they did not remember too clearly. His school has also provided access to an occupational therapist, to help with their son's sensory needs. Additionally, they were involved with the Coaching Families program and the psychoeducational support group. Jasmine and her family were involved with the Coaching Families program for a few years prior to the beginning of the current study. Jasmine and Clarence had been involved with the Coaching Families program for approximately six months at the beginning of the research project. Their "mentor" was the facilitator for the psychoeducational support group, which is how they became involved. Jasmine had been a regular member at the Coaching Families support group, even prior to becoming officially involved with Coaching Families and being assigned a mentor from the program. Before the study, Jasmine had attended the psychoeducational support group for approximately a year and a half. The programs they were

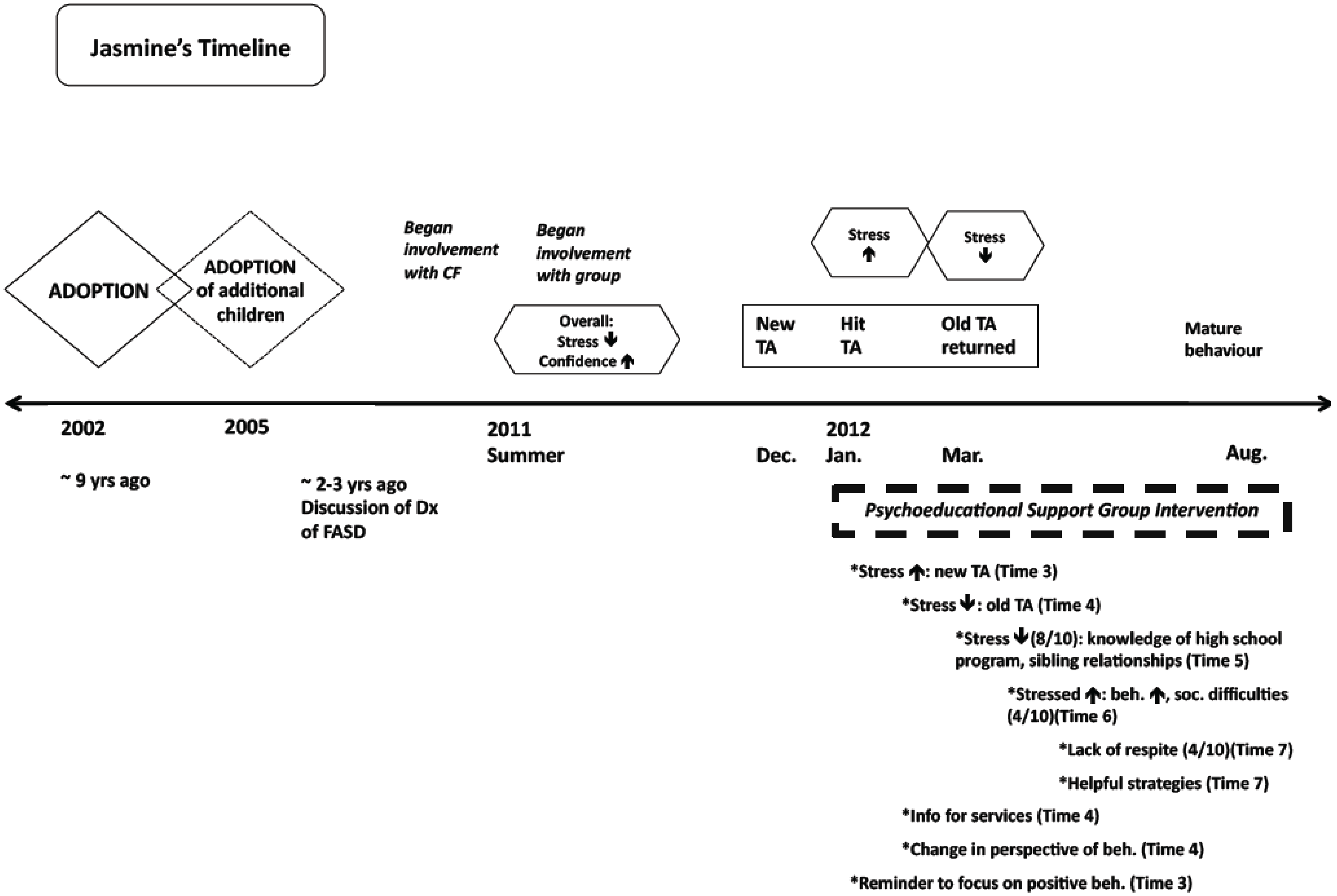

Figure 4. Overview of timeline for Case One: Jasmine.

currently involved with at the time of the research project included Coaching Families and respite services. There are several services that Jasmine has found particularly helpful, including Coaching Families, respite services, and the educational support their sons receives through an teaching assistant and modified Grade 9 program. In general, Jasmine and Clarence feel that they have been able to access everything that they have required, with the exception of the McDaniel Youth Project (Catholic Social Services, 2013). The McDaniel Youth Project is a Catholic Social Services mentorship program that focuses on helping youth access community supports in order to support a successful transition to adulthood (Catholic Social Services, 2013). Unfortunately, at the time of the research project there was a long waitlist to join the program. Jasmine was hoping to find a similar program that would be available for her son. Ideally, Jasmine would like to see a program that helps her to learn more about her son's transition to adulthood, and the things that she should think about to help support that transition, such as guardianship and guardianship arrangements

Case two: Terry. Terry is a successful professional in her late forties who works as a technology consultant. She lives in a suburban middle-class home in a large Canadian city with her husband and eight year old son, whom she and her husband recently adopted. At the time of the beginning of the research project, Terry's son, Tyson, had been living with them for two months and Terry was taking a break from her job while her son settled in to his new home. Tyson was eight years old and has been diagnosed with FASD and ADHD. Figure 5 provides a cursory overview of Terry's timeline since she begun the journey of adopting her son.

Terry and her husband had made the decision to adopt a child one year before they adopted their son. Terry and her husband felt they were lacking some focus in their life. They had decided early on in their marriage that they were not going to have children. Terry and her

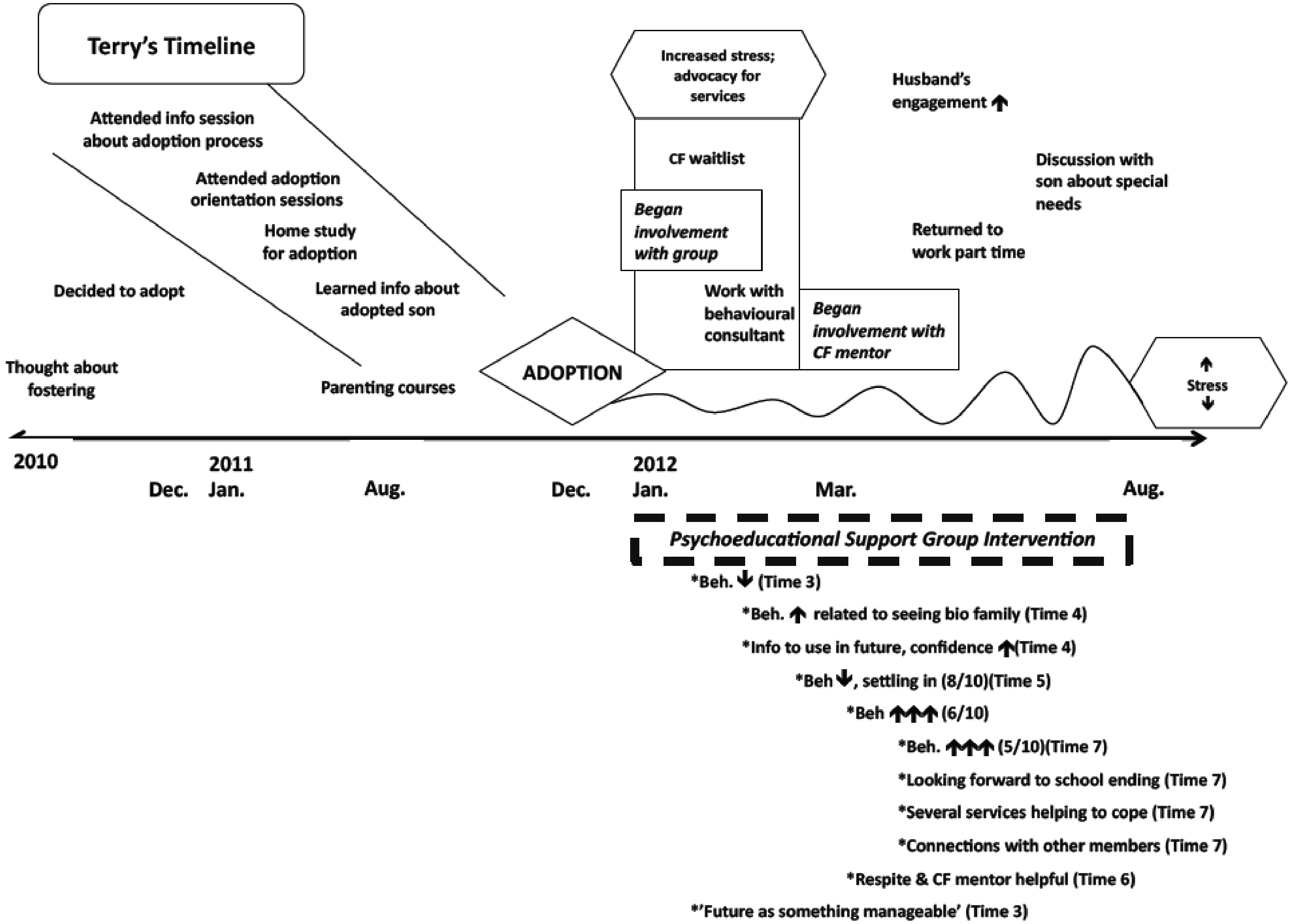

Figure 5. Overview of timeline for Case Two: Terry.

husband got married in their early thirties and it was not until they were both almost forty that they began thinking about having children. They felt that something was missing and that they had to do something to address it. Terry brought up the potential of fostering children, and her husband then brought up the idea of adoption.

Terry and her husband attended an information session at Alberta Human Services. Within a week they had begun the application process and had signed up for orientation sessions, which is one of the first steps to the adoption process. The orientation sessions take approximately 24 hours and there are eight modules in total. Terry felt she really clicked with the other attendees of the orientation sessions and she was able to share many ideas with them. At the beginning of this process, Terry reported that she was interested in adopting a sibling group, and that there was one sibling group of three (two girls and a boy) that she had been thinking about adopting for a few months. It was thinking about this sibling group that motivated Terry to begin the process. It was during the orientation sessions that Terry received a lot of information regarding children in care and when she was first told about FASD. Terry reported that during the orientation sessions, they talked very openly about FASD and what that meant. During the sessions, Terry was told that approximately 80% of children in care are affected by FASD. Terry reported, "we started accepting that fairly early on" (23/T2/Line235), and that she was grateful for the information because it allowed her to prepare early on in the process, and gave her time to learn more about FASD by researching and taking out books on the subject. Terry found the book, Damaged Angels by Bonnie Buxton, particularly helpful.

Following the orientation sessions, Terry and her husband had to complete a large questionnaire that was given to individuals completing a "home study" of Terry's home environment over a 30-day period. The home study consisted of five home visits and several interviews. It is an evaluation to determine if the home is a suitable environment for an adopted child, but also provides information to the adoption workers to see if Terry and her husband would be a good fit for the children. Throughout this process, Terry and her husband discussed the possibility of adopting a child with special needs, which they were both fairly open with. Information gathered for the adoption workers is shared with the social workers of the children currently in foster care. Based on the information gathered in the home study, a report was written and sent to Terry and her husband to review. Terry said she did not find the home visits and interviews stressful. However, she had attended some counselling during the beginning of the process that had helped her to deal with some particular issues related to her own upbringing, which had made it easier to talk about her own upbringing during the home study interviews.

Terry became worried at the length of time it was taking to complete the home study. During the home study process, the sibling group she had previously wanted to adopt had already been adopted, which was somewhat painful for Terry. Terry attended adoption fairs and put in a few inquiries of sibling groups, but nothing came about. Terry was approached with a sibling group aged three, four, and five, all of which had FASD. It was at that point that Terry and her husband began thinking that maybe a sibling group would be too much for them to handle, which was echoed by their adoption worker.

By the fall, approximately 10 months after they had begun the adoption process, they learned more about their son. At his last foster placement Tyson had made "leaps and bounds" (23/T2/Line401) because of the individual attention he was receiving, and possibly because he had been separated from his older brother, whose behaviour often escalated him as they fed into one another. It was then that Terry and her husband decided they wanted to proceed with the adoption. Terry spent a month getting prepared for his arrival, which included informing their community school that he would soon be arriving. They met Tyson at his foster home for a few hours, which Terry believed went really well. Terry and her husband stayed in the area for a few days, and then the following weekend their soon-to-be son came for a weekend visit. The following weekend they picked him up and he drove home with them. It was December before the process was completed, which Terry indicated was a difficult time for them because of the holiday and all the expectations that surround that time of year.

Terry and her husband have accessed a few different types of services since they adopted their son. Most of the services they have accessed through individuals working with them through the adoption process. The services have included working with social workers, OT, SLP, psychiatrists, respite services and youth workers. At times, Terry and her husband had to advocate for additional services on behalf of their son. At the beginning of the study, Terry was on the waitlist for a Coaching Families mentor. She had been informed of the Coaching Families program from CASA when she advocated for additional services. The intake worker for Coaching Families informed Terry of the support group and she attended the next meeting (Time 1). Terry and her family were assigned a Coaching Families mentor during the study (Time 5).

Case three: Janelle. Janelle is a single woman in her early twenties with an eight-year-old daughter, Sarah. Janelle and Sarah live in an apartment in an urban centre of a large western Canadian city. At the beginning of the study, she worked at a daycare facility, but lost her job during the study. She has ambitions of starting another career and possibly going back to school. She has had a permanent guardianship order (PGO) for Sarah for approximately a year and a half, and Sarah has been in her care for approximately three years. Janelle has been assigned an adoption worker and during the study she was in the process of adopting her daughter. Figure 6

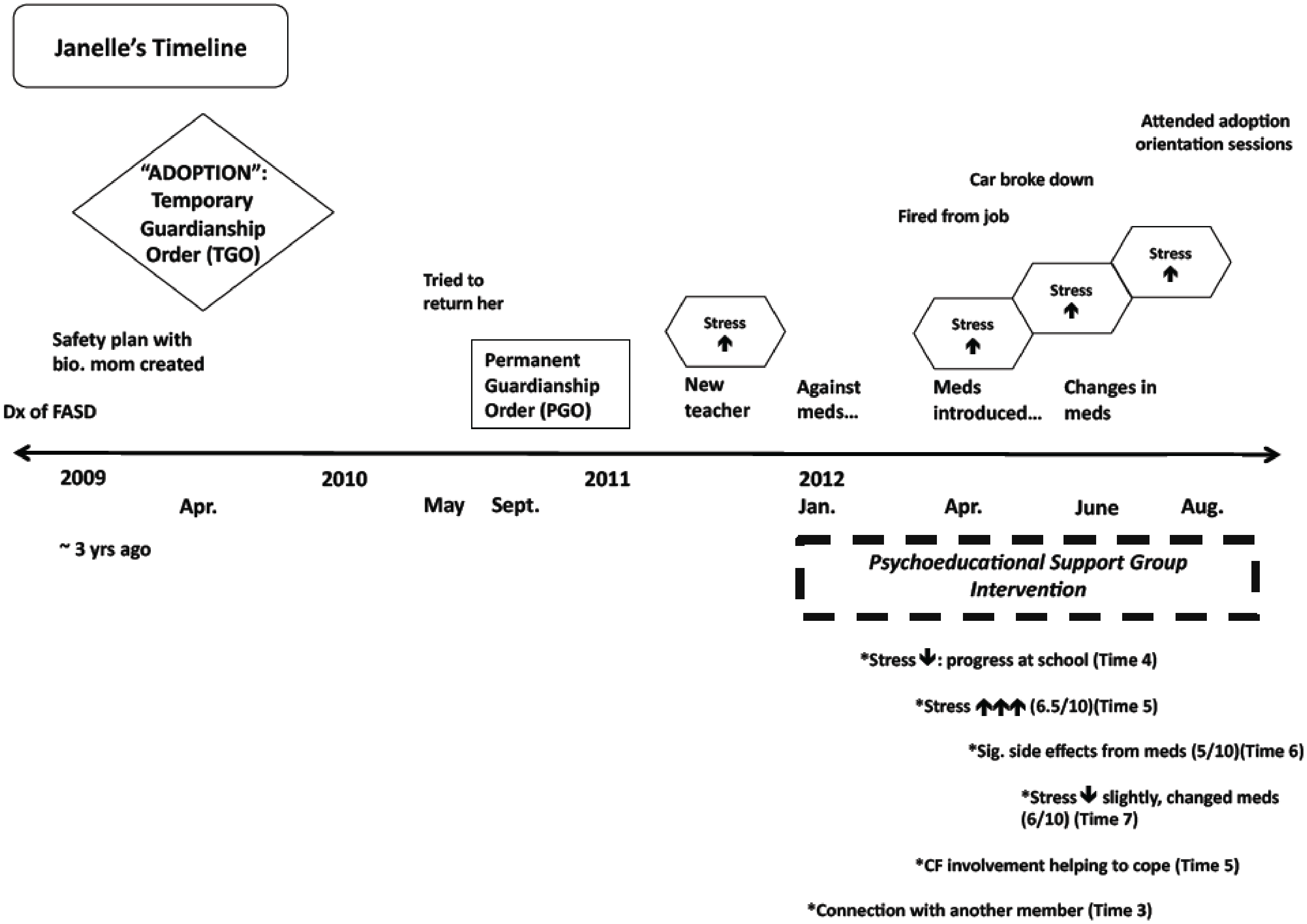

Figure 6. Overview of timeline for Case Three: Janelle.

provides a cursory overview of key events of Janelle's adoption of her daughter and her involvement with the Coaching Families psychoeducational support group.

Janelle describes herself as a kinship caregiver. Janelle met Sarah at the daycare where she is employed when Sarah was approximately one-and-a-half years old. When her daughter was younger, Janelle would often support Sarah's biological mother by providing respite without pay. Janelle would take care of Sarah during weekends. She would often buy Sarah clothes and take groceries to Sarah's house to help them out, because they often did not have enough food. Sarah's biological mother has a history of difficulties with substance and alcohol abuse. Sarah's biological mother created a safety plan for Alberta Human Services regarding what would happen to Sarah if anything happened to her, and Sarah's biological mother approached Janelle to be apart of that plan. At the time, Janelle believed there would only be a slight chance that Janelle would begin taking care of Sarah; she also believed it would only be a few days and then Sarah would return to her biological mother. However, she quickly realized that was not going to be the case. When Sarah's biological mother relapsed, Janelle began taking care of Sarah. At the time of the study, Sarah has been in Janelle's care for three years. During this time, Sarah has continued to have a relationship with her biological mother, until recently when all access to biological family, including her eight siblings, had been terminated with the exception of one nephew who is also in care.

Sarah was diagnosed with FASD 10 days before she came into Janelle's care. It was during the assessment process that Janelle began taking care of Sarah. Janelle indicated through this process Sarah's biological mother began to realize the possible effect of prenatal alcohol exposure may have had on Sarah's development, and as Janelle describes she started to "slip" (25/T2/Line1045). This was one of the reasons that Janelle believed that it would only be a temporary situation. She believed Janelle's mother would "get back together" (25/T2/Line1047). As Janelle describes:

> She called me the day she found out that Sarah had FASD. She was distraught. Just, "What have I done to my own child?" That's where I have empathy. There are a lot of horrible, hurtful things that she's done, but I can't imagine knowing that your actions affected somebody for the rest of their life. And it devastated her. It was horrible. I took Sarah that day for about four days, and after four days I couldn't get a hold of her. (25/T2/Line1047)

For the first six months, Sarah was under Janelle's care under a temporary guardianship order (TGO). The TGO was renewed for another six months. Janelle describes the initial process of the TGO as happening very quickly. The social worker for Sarah's case came to her house in order for Janelle to sign some papers and for Janelle to complete a police check application. Janelle had just moved out of her mother's house with a roommate and did not have a driver's license. Sarah's biological mother disappeared for four months. Janelle described that it was somewhat awkward at first. Prior to this, Janelle thought of their relationship as more like sisters. Janelle would take Sarah out to eat at Boston Pizza and would eat candy and junk food together. After Sarah came into her care, Janelle had to move from being a sister figure to being her mother, and had to tell her to "do your homework" or "take a bath". Janelle was initially in shock, but after two months she realized that they were a family.

After a year of being in Janelle's care, Sarah was to be returned to her biological mother's care. However, Janelle believed Sarah would be unsafe in that environment, due to very distressing behaviour Janelle witnessed while walking outside. As a result of this behaviour, Janelle got a Child and Youth Advocate involved and also wrote a letter to the Minister of

Alberta Human Services protesting Sarah being returned to her biological mother due to unsafe conditions. These actions caused Sarah's file to be temporarily put on hold, and the decision of the returning Sarah to her biological mother was reversed. Sarah's file was transferred to the Alberta Human Services District Manager for Edmonton, who at the time was the only person who could make decisions regarding Sarah's placement. Janelle was given PGO status. However, the PGO status was a process that took approximately one year, because Sarah's biological mother would periodically fight against the PGO. After one year, Sarah's biological mother signed the PGO during a three-day trial and now Janelle is in the process of adopting Sarah.

As part of the adoption process, Janelle has been asked to attend orientation sessions, similar to the series that Terry attended, in order to move forward with the adoption. People who are interested in becoming foster parents are also required to attend. At the end of the second interview, Janelle was particularly annoyed that she had to attend these sessions after caregiving for her daughter for over three years, and that it would be the entire weekend: "Really? Three years and two months later you're sending me? Come on, I could teach this course!" (25/T9/Line230). She was particularly annoyed that childcare was not provided, so she would have to find someone to look after her daughter for the weekend.

Janelle has accessed the Coaching Families program, counselling services, and dietitians. As a guardian with PGO status, she is still navigating and learning about the services that are available to her as a parent. Janelle was provided with the opportunity to leave her daughter with a foster care worker as respite. However, she feels uncomfortable leaving her daughter with individuals that she does not know. Additionally, Janelle described several difficulties her daughter experiences due to attachment issues, which makes using respite services difficult because of the emotional toll it puts on her daughter. In the past, Janelle's mother had taken care of Janelle's daughter so she could be provided with a break, but Janelle's mother recently moved into a smaller place so she's no longer able to take her for overnight visits, which has decreased the amount of respite she has received. At times, her brother has provided some respite for a few hours at a time, since he has moved into her building. Janelle is still navigating which services she has access to as a guardian with PGO status. Once she is her permanent guardian, she will be able to access FSCD funding, which will help pay for respite services.

Janelle had been involved with the Coaching Families program for approximately six months at the beginning of the research project. Her assigned social worker with Alberta Human Services first informed her of the program. Janelle realized that as the adoption progressed the services provided to her through Alberta Human Services would eventually be withdrawn, which solidified her decision to become involved with Coaching Families. When she first called Coaching Families, Janelle was told about the psychoeducational support group. Janelle accessed the psychoeducational support group while on the waitlist for a mentor, which took approximately five months. With the exception of the funding for respite services, Janelle indicated that she has not come across many barriers when attempting to access services. However, Janelle described that it is hard to find resources or services in the community. Janelle reports, "It seems like I don't really know- or feels like I just don't know what else is out there, apart from Coaching Families. Like, there seems there got to be more than this, you know? I just don't know what there is" (25/T2/Line795).

Research Question A: A Priori Factors

The goal of the analysis was to determine themes related to caregivers' experiences of "a priori" categories: stress, parental sense of competence, social support, and quality of life.

Descriptive and raw scores from quantitative measures were first reviewed and compared to information that emerged from deductive coding of interviews, feedback forms, and observations. Reviews of qualitative data began following interviews and during transcription. Coding memos were kept throughout the process, and themes were generated from initial codes and redefined over time after being refined, peer reviewed, and member checked. The following is information that emerged through analysis. Excerpts from data sources, as well as descriptive and raw quantitative data, are provided in order to provide support for the reader.

Case one. The following sections provide information regarding Jasmine's experiences, both her specific experience of the psychoeducational support group and broader experiences, related to the prefigured or "a priori" categories previously discussed. Jasmine's broader experiences are provided for contextual information. Although these categories are posed as separate factors, they are also inevitably linked. Connections between the a priori factors are discussed as appropriate. Information was gathered from both quantitative (i.e., questionnaires) and qualitative (i.e., interviews, feedback forms, observations) sources.

Caregiver stress. Several areas of sources of stress were identified for Jasmine, as well as aspects that help her deal with stress, both of which are discussed below.

Information gathered from multiple sources revealed several sources of stress for Jasmine: chaos in the household (i.e., PSI/SF [T1 and T8], interviews [T2 and T9]), Logan's lack of friendships and social skills (i.e., interviews [T2 and T9], feedback form [T6], and observations [T6]), being uncomfortable with using respite services (i.e., CFS [T1 and T8], interviews [T2 and T9], feedback forms [T5 and T6]), experiences with the school system (i.e., interviews [T2 and T9], feedback form [T3], observations [T3]), dealing with issues of guardianship (i.e., interviews [T2 and T9]), and her son's and daughter's behaviour (such as

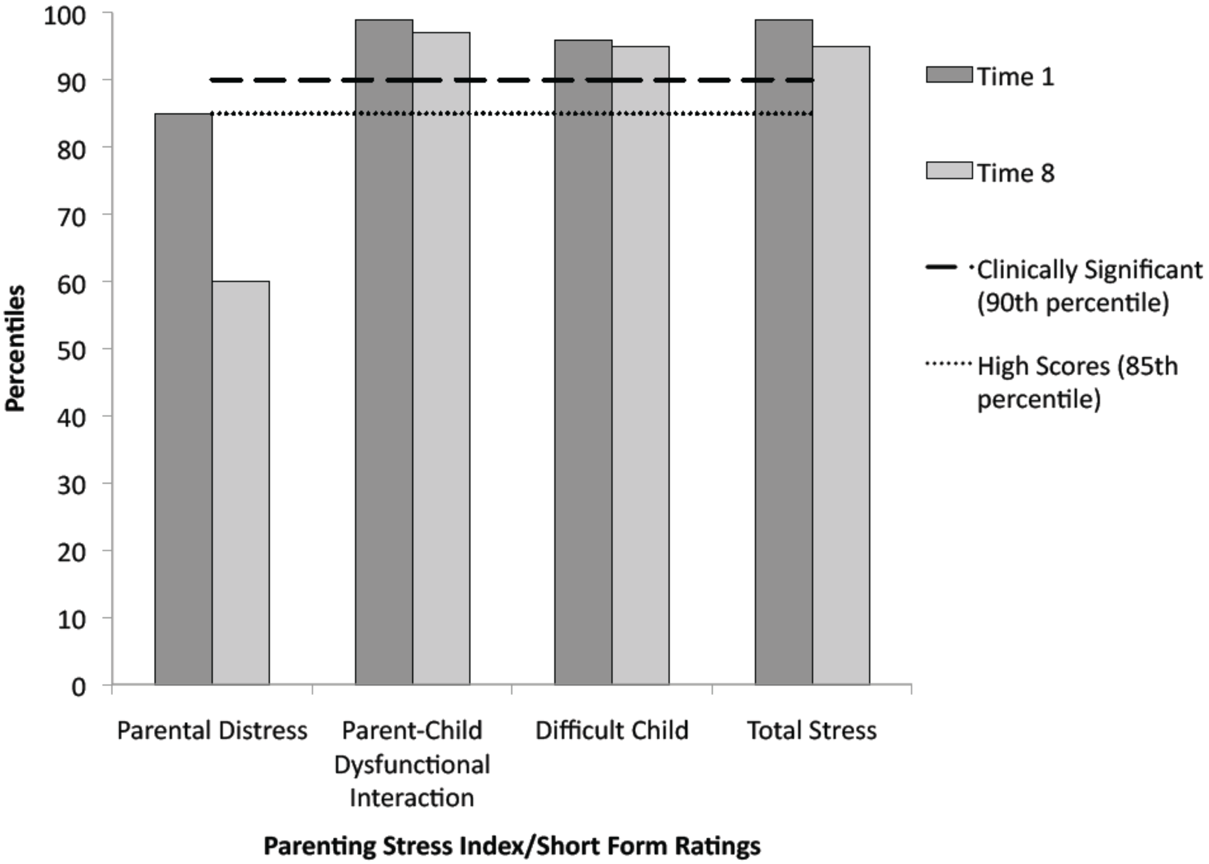

Figure 7. Percentiles of parenting Stress Index/Short Form (PSI/SF) ratings by Case One: Jasmine

sneaking food; i.e., PSI/SF [T1 and T8], interviews [T2 and T9], observations [T6], feedback forms [T5 and T6]) were all indicated as sources of stress.

Jasmine's responses on the PSI/SF and the CFS both suggested Jasmine is experiencing significant amounts of stress overall (see Figure 7 for Jasmine's ratings of stress on the PSI/SF; see Figure 8 for Jasmine's responses on the CFS). On the PSI/SF, Jasmine's responses indicated clinically elevated levels of stress (at or above the 90th percentile) on two of the three measured factors (Parent-Child Dysfunctional Interactions and Difficult Child) as well as on the Total

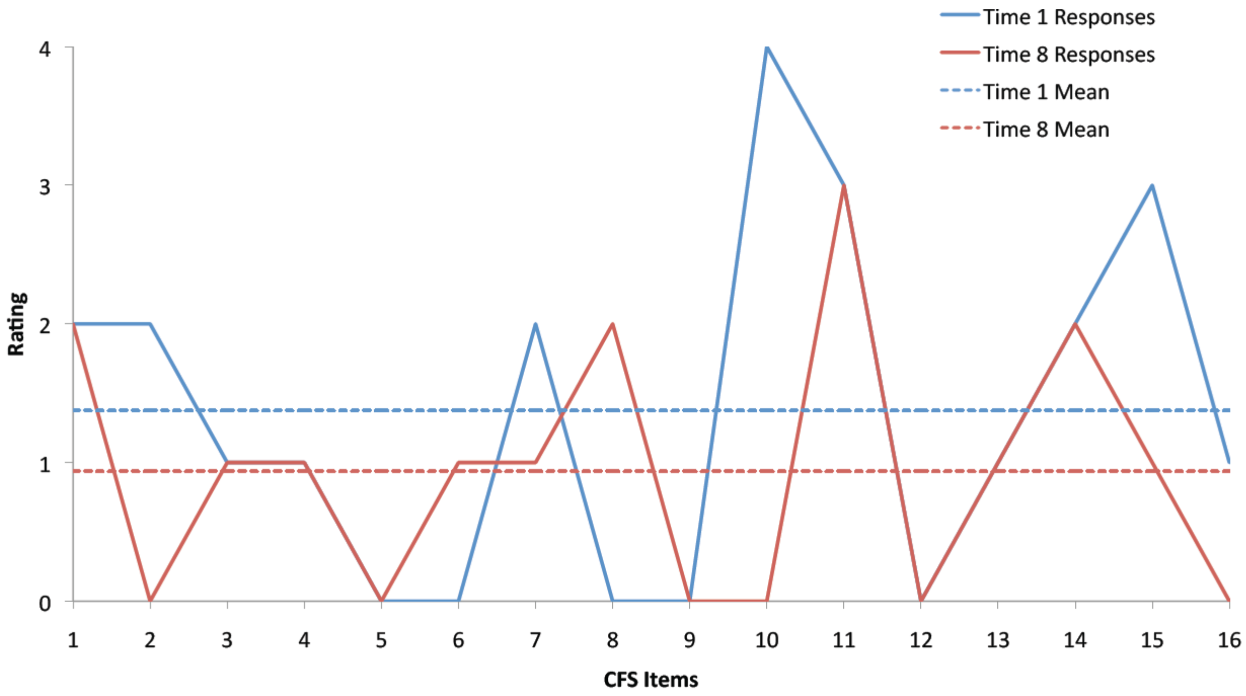

Figure 8. Coaching Families FASD Stress Scale (CFS) ratings for Case One: Jasmine. Ratings range on a five-point scale from *never* (0) to *constantly* (4), indicating higher scores equals greater stress levels.

Stress score, both on pre- and post-intervention measures. Jasmine's pre-intervention ratings on the Parental Distress subscale of the PSI/SF also suggested stress in the "High" range (at or above the 85th percentile); however, her ratings on the post-intervention PSI/SF suggested Parental Distress ratings to be within average limits (60th percentile).

When interviewed about her stress being significantly elevated on the PSI/SF, with her Total Stress score falling at the 95th percentile, Jasmine reaffirmed that this reflected her experience. She indicated this was particularly true when all of her children are at home at once, as indicated during the post-intervention interview: "Sitting here, I don't feel that stressed, but, geez, once the kids all come home, and when they're all here - okay then I feel stressed!"

(22/T9/Line1404). It was not just dealing with her son's "issues" (22/T9/Line2158) that increases her stress, but the combination of his behaviour with that of her daughter with ODD, which reiterated Jasmine's high scores on the Parent-Child Dysfunctional Interactions and Difficult Child subscales.

On the PSI/SF, Jasmine indicated that her son's difficulties making friends was a source of stress, which was also supported by interviews (i.e., T2 and T9), feedback form (i.e., T6), and observations during sessions (i.e., T6). In interviews with Jasmine, she described her son as having one friend in the neighbourhood and no particular friends at school, which can make her sad. Jasmine and Clarence have tried to provide advice to their son about specific social skills (e.g., not standing to close to people) without direct results. Jasmine and Clarence continue to try to provide coaching for Logan in specific social situations. Overall, Jasmine's son likes to spend time alone. It continues to be a source of stress for Jasmine, but she indicated she hopes Logan will make new social connections in the new high school program he will be attending next year.

Jasmine's overall high level of stress was also reflected by her responses on the CFS (questions on the CFS can be found in Appendix H). First, prior to the intervention, Jasmine indicated on the CFS that she is constantly uncomfortable using respite services; however, by the end of the intervention this stress had greatly decreased as Jasmine began to see its value, despite Logan's protests. This information was congruent with interview information (i.e., T2 and T9), feedback forms (i.e., T5 and T6), and information gathered on the PSI/SF. Additionally, Logan had attended an overnight respite program that was particularly helpful. Second, prior to the intervention, Jasmine also indicated that she was often frustrated with the school system. Again, this concern had greatly decreased by the time the intervention had concluded. Logan had been accepted into an appropriate program for high school, which Jasmine and Clarence were relieved about, especially because Logan's current school year had been so turbulent. Logan had been assigned a new teaching assistant in December, which Jasmine indicated had really affected Logan's work production. Additionally, Jasmine's stress had drastically increased when Logan hit his new teaching assistant sometime in the New Year, as indicated by feedback forms (i.e., T3) and observations (i.e., T3). As a result, Logan's old teaching assistant was returned. Jasmine suggested it was a combination of having his old teaching assistant returned and learning he had been accepted into an appropriate high school program helped Logan to finish out the school year well, and reduced a significant source of stress for Jasmine. Third, both before and after the intervention, Jasmine also indicated on the CFS she is frequently stressed about her family's financial situation. Finally, feeling tired/exhausted, worrying about how her son's behaviour will affect her other children, avoiding participating in family social events, running out of ideas of how to parent her son, and arguing with her husband about parenting (prior to the intervention) were all indicated as somewhat being sources of stress for Jasmine on the CFS.

In interviews, Jasmine also indicated she worried about guardianship for Logan as he transitions into adulthood. Prior to Jasmine's involvement with the Coaching Families program, Jasmine and Clarence had been particularly concerned about Logan's future. However, as Jasmine's participation in the program progressed and she became more and more knowledgeable about Logan's strengths, as well as about FASD, her hope that Logan would be able to live independently grew. "They are capable than more than we thought they were capable of. Like, honestly, I didn't think he'd ever really have a career…Before [our mentor] came, we thought 'Oh, he'll be in a group home'" (22/T9/Line1680). Jasmine's perception of her son's abilities changed as she learned more about FASD and her son's strengths. Now Jasmine and Clarence are hoping that Logan will be able to live somewhat independently when he moves into adulthood: "We're hoping he's going to be able to have a place, with somebody assisting him with the money" (22/T2/Line292). As stated previously, Jasmine indicated this was a program area of need for her and her family, and suggested an ideal program would address the issues that they will face as Logan matures. For instance, if someone would be available to help Logan with the finances of living independently if something were to happen to him or her. As such, this continues to be an area of stress for Jasmine.

Finally, a major source of stress for Jasmine continues to be difficulties with Logan's behaviour, as indicated by information gathered from PSI/SF (i.e., T1 and T8], interviews (i.e., T2 and T9), observations (i.e., T6), and feedback forms (i.e., T5 and T6), as well as the behaviour of Logan's younger sister. Jasmine indicated Logan does not spend a lot of time with his siblings. Logan sometimes does not realize his own strength when playing with his younger siblings, and therefore, despite their lack of a close relationship, Jasmine is somewhat relieved that she does not have to worry about the safety issues as she would if they played closely. In addition to Logan's aggressive behaviour at school, difficulties with peer and sibling relationships, and not being aware of his own strength, Jasmine was also concerned about Logan sneaking and hoarding food. Although it was not a major concern for Jasmine, it was to be an added stressor for the family. Over the course of the study, Jasmine and Clarence reported that Logan had matured: "He's asking to get a job at McDonalds, he's asking even about getting his learner's…he wants to try piano lessons" (22/T9/Line246). Jasmine reported this mature behaviour had also translated into better relationships with his siblings. At the time of the study, Logan had been accepted into a high school program that he was looking forward to, which Jasmine and Clarence believe had spurred his recent mature behaviour: "Just knowing he's heading into high school and, I think, he realizes it's not that long until he'll be out on his own"

(22/T9/Line246). Since learning about the program, Logan's behaviour had somewhat deescalated. He used to "blow-up" (22/T2/Line505) almost every day, but after learning about the program his "stubbornness" (22/T2/Line512) and blow-ups had significantly decreased. Jasmine indicated she continues to have to remind Logan to complete tasks, but he often listens rather than fighting her requests. By the end of the study Logan's behaviour had begun to mature, which was a relief for Jasmine. Additionally, Jasmine had learned several strategies for ignoring her daughter's behaviour, which was also helpful. Jasmine indicated several other sources of support that help her to deal with stress, including her participation in the psychoeducational support group and the Coaching Families program. Sources found outside the psychoeducational support group are discussed, followed by aspects of the intervention that Jasmine found particularly helpful for stress management.

Overall, having the time to reflect and rejuvenate were key ways for Jasmine to reduce her stress. Information gathered from Jasmine through questionnaires, interviews, and feedback forms all indicated that Jasmine's stress was helped when she had some time to gather her thoughts or take a breath. This particular theme was evident in several ways: in her participation in several programs (including the psychoeducational support group, Coaching Families, respite programs, and summer camp for Logan), along with the social support she received from her husband, and the few minutes she could grab at home to be alone. For instance, as indicated on the CFS and through interviews, Jasmine indicated respite services was a key aspect to help deal with the chaos and stress in her home – and as she indicated, "just having a break" (22/T2/Line316), despite her previous concerns due to Logan's negative experiences. It was not until they had gotten involved with the Coaching Families program that they learned that they were eligible for financial support through Family Support for Children with Disabilities

(FSCD), and that through their FSCD Agreement with Alberta Human Services, they were eligible to receive funding for respite services. Prior to being involved with official respite support, Jasmine's mother would provide some unofficial respite by spending time with Jasmine's children. When talking about respite services, Jasmine appeared somewhat apprehensive and possibly guilty for accessing the service. She stated, "He doesn't like it, but for us it's great!" (22/T2/Line214). Specifically, Jasmine indicated there are certain activities, such as going to the movies or going to church, where she knows her son will just "act out" (22/T2/Line217); "he's active…never listening, fidgety, and then he gets the other girls going" (22/T2/Line220). By taking their son to respite services, even for a few hours a week, provides members of the family with an opportunity to attend events they may not otherwise have been able to attend. It also provides their son with the opportunity to have a break from his younger siblings, and to spend time with other children his age. Summer camps also provided a "break", along with fostering connections with other campers for Logan, which helped to reduce Jasmine's stress in the summer months. Furthermore, having time at the end of the day where she could let loose her frustrations and discuss her concerns and worries with her husband was also a particular source of relief of stress, "Just being able to get it all out and just talk about it with him" (22/T2/Line321). Without this social support, Jasmine reported her stress would continue to climb. Finally, although Logan's school experience was at times an area of stress for Jasmine, it would also be an area of support when Logan was progressing well and he was receiving the individualized support that Jasmine believed he required to be successful.

Participating in the psychoeducational support group was also reported by Jasmine in interviews and feedback forms to help with stress. Jasmine indicated on the rating scale of the intervention components that the group was *very helpful* for "feeling less stressed as a parent"

(22/T8/Question12h). The benefits of participating in the group were helpful to Jasmine in reducing or managing her stress. Focusing on the positives, changing her expectations, learning that much of her son's behaviour was typical for a youth his age, hearing the stories of others, and gathering additional strategies and resources were all reported by Jasmine to be helpful to reflect on her son's behaviours and her concerns, which in turn helped her to deal with daily stressors. Jasmine indicated she knew nothing about FASD prior to being involved with Coaching Families and the psychoeducational support group. The facilitator has helped them to develop specific strategies to help with different situations that they come across. It also helped them to differentiate between typical youth behaviour and behaviour that could better be attributed to the neurobehavioural brain-injury associated with FASD. Their Coaching Families mentor helped them to become knowledge of their son's strengths and weaknesses and related difficulties with FASD, as prior to her involvement she reported she knew little about FASD Jasmine indicated she did not know where she would be if she had not received the support they had through the Coaching Families program, as before getting involved with the program, she indicated she did not know anything about FASD. She appreciated hearing how other participants dealt with particular situations, which she could then recall when faced with stressful situations. Furthermore, being reminded that much of her son's behaviour was positive and that it could be "much worse" (22/T2/Line891), as illustrated by stories from other participants, was also helpful. Jasmine indicated that the group helped her to "have more confidence in Logan's abilities" (22/T8/Question22). Finally, learning more about FASD through the information sessions and discussions provided additional relief, although this knowledge did not always translate into feelings of parental competence (see below). Once more, the psychoeducational support group provided Jasmine with the much needed space and time to reflect on her own experience in an environment where she felt connected and supported. Overall, Jasmine indicated on the FQOL she was *very satisfied* with the support her family receives to relieve stress.

Questionnaire, interview, and feedback form data suggested Jasmine’s stress decreased slightly over the course of the intervention due to various factors in her life (see also Figure 4 for an overview of Jasmine’s experience). Overall, sources of stress for Jasmine were decreased over time, including Logan’s behaviour, her relationship with her son’s school, and issues related to guardianship. This was a result of several factors, including timing, Jasmine’s increased knowledge regarding FASD, her own increased sense of knowledge and parental competence, and a reduction in Logan’s maladaptive behaviour. In particular, both Logan’s change in behaviour and learning about Logan’s upcoming high school program has greatly reduced her anxiety. The psychoeducational support group may have provided additional contextual information for Jasmine that helped her to focus on the positives, which helped to increase her own internal resources and decreased her negative appraisal of the situation.

Caregiver sense of competence. Information about Jasmine’s feelings of parental sense of competence, and her related experience of the psychoeducational support group, was gathered primarily through interviews and PSOC questionnaire. Interviews indicated five themes related to Jasmine’s feelings of parental competence, and survey data provided additional information about Jasmine’s levels of perceived competence. The five themes were as follows: positive reinforcement, patience, parental knowledge, reassurance, and strategies.

It was not until Jasmine was involved with the psychoeducational support group and the Coaching Families program that Jasmine realized the lack of positive language they had used in their home. “We were not positive with him at all. Honestly, probably the first four or five years we were like, 'You're doing that wrong. What are you doing? You're supposed to do this.' …We just tried to use trial and error" (22/T2/Line689). By using positive reinforcement, Jasmine indicated that their son's behaviour became more manageable and she began to feel more confident as a parent. Moreover, Jasmine identified her patience was a particular strength for her, as he will often required several reminders to accomplish tasks. Likewise, through her involvement with Coaching Families and psychoeducational support group, her knowledge of parenting and parenting a child with FASD in particular has increased. Despite her progress as a parent, Jasmine continues to feel she lacks confidence as a caregiver: "I'd say I'm more knowledgeable than confident" (22/T9/Line1625). Before she had kids, she had imagined she would be more confident than she felt:

> I thought I'd be like my mother. She seemed to just do it, naturally. And it didn't seem to come naturally, I don't think for either of us. We both were just thrown in… Neither one of us is really a confident person anyways…We're just trying our best. (22/T9/Line1561).

Jasmine's lack of sense of competence as a parent was also reflected in her responses on the PSOC. Overall, Jasmine's Total, Satisfaction, and Efficacy parenting self-efficacy ratings are somewhat low in comparison to the ratings of 280 mothers reported by Johnson and Mash (1989) when the PSOC was first created (more than one standard deviation above the mean indicating lower self-efficacy in comparison). Although the PSOC does not have a normative comparison group, these results do provide further evidence that substantiates the qualitative information provided by Jasmine in interviews, as well as stress ratings on the PSI and CFS. Although Jasmine's responses on the PSOC varied from question to question, Jasmine's Total rating, both pre- and post-intervention, was ranked between *disagree* and *agree* ($M = 3.4$) for such questions as "Being a parent makes me tense and nervous" (see Appendix I for the questions on the PSOC

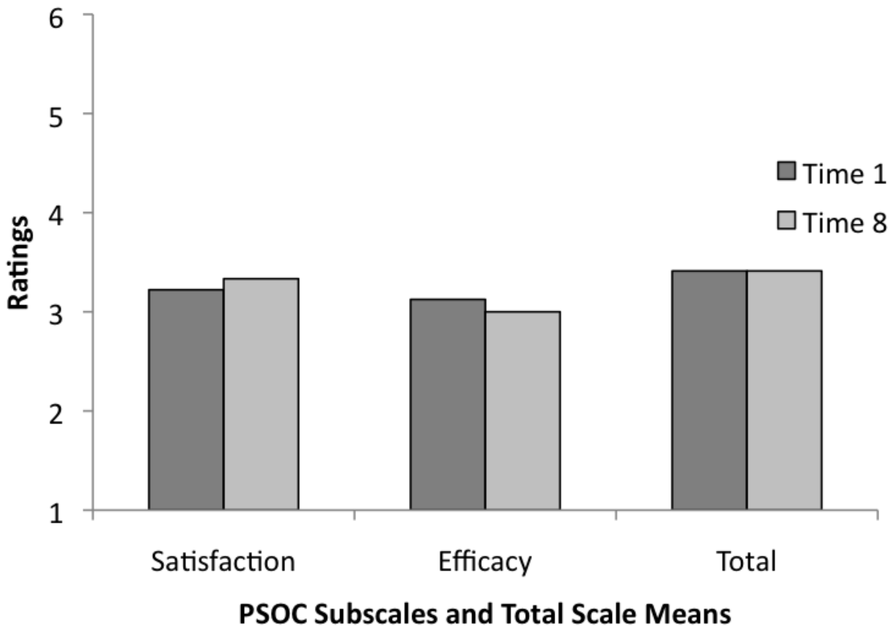

Figure 9. Parenting Sense of Competence Scale (PSOC) ratings for Case One: Jasmine. Ratings range on a six-point Likert scale from *strongly disagree* (1) to *strongly agree* (6), indicating lower scores equals greater self-efficacy.

and see Figure 9 for visualization of the means). For example, Jasmine indicated she *strongly disagreed* when asked, "My mother was better prepared to be a good parent than I am." Jasmine's responses on the Satisfaction subscale, both pre- and post-intervention, were also ranked between *disagree* and *agree*, indicating at times it is difficult for her to manage (*M* = 3.2 and 3.3, respectively), whereas Jasmine's responses on the Efficacy subscale, both pre- and post-intervention, were closely ranked to *disagree* indicating Jasmine feels problems related to parenting can somewhat be easily solved (*M* = 3.1 and 3.0, respectively). Finally, Jasmine indicated on the rating scale of intervention components that the group was only *somewhat* *helpful* to help her "feel more confident as a parent" (22/T8/Question12i). All of this information suggests Jasmine experiences difficulties managing and does not feel confident as a parent.

Due to her lack of self-efficacy, Jasmine finds it beneficial to receive reassurance from outside sources. She often finds reassurance from her Coaching Families mentor, but from other parents at the psychoeducational support group as well:

> We still don't really know that what we're doing is the right way to do it. We need reassurance. We'll throw something by [our mentor] and she'll tell us, 'That was good'… In general, I don't think we're very confident. (22/T9/Line1517)

The reassurance reminds Jasmine that she is on the right track, even if she feels she may be using trial and error to solve individual problems. Most importantly, successfully employing a strategy or Logan "listening to what I'm actually saying" (22/T2/Line91) helps Jasmine to gain the most confidence as a parent. Jasmine finds it helpful to learn new strategies at the psychoeducational support group and to learn from other parents what they do in certain situations.

Family support. Information about Jasmine's social support, including concerning the psychoeducational support group, was gathered through interviews and the FSS questionnaire. Jasmine's ratings on the FSS can be found in Figure 10. Jasmine's social support was mapped onto the five areas assessed by the FSS: kinship, spouse/partner, informal, programs/organizations, and professional support. Overall, Jasmine's responses on the FSS indicate her total social support to be ranked between *sometimes helpful* and *generally helpful* (M = 2.3). Jasmine receives more support from formal professional services (M = 3.0), which she finds *generally helpful*, than she reports to receive from more informal sources (e.g., support from kinship, spouse, informal, and programs/organizations; M = 2.1). Specific items on the FSS indicate she finds the support she receives from her parents, spouse, social clubs, parent group

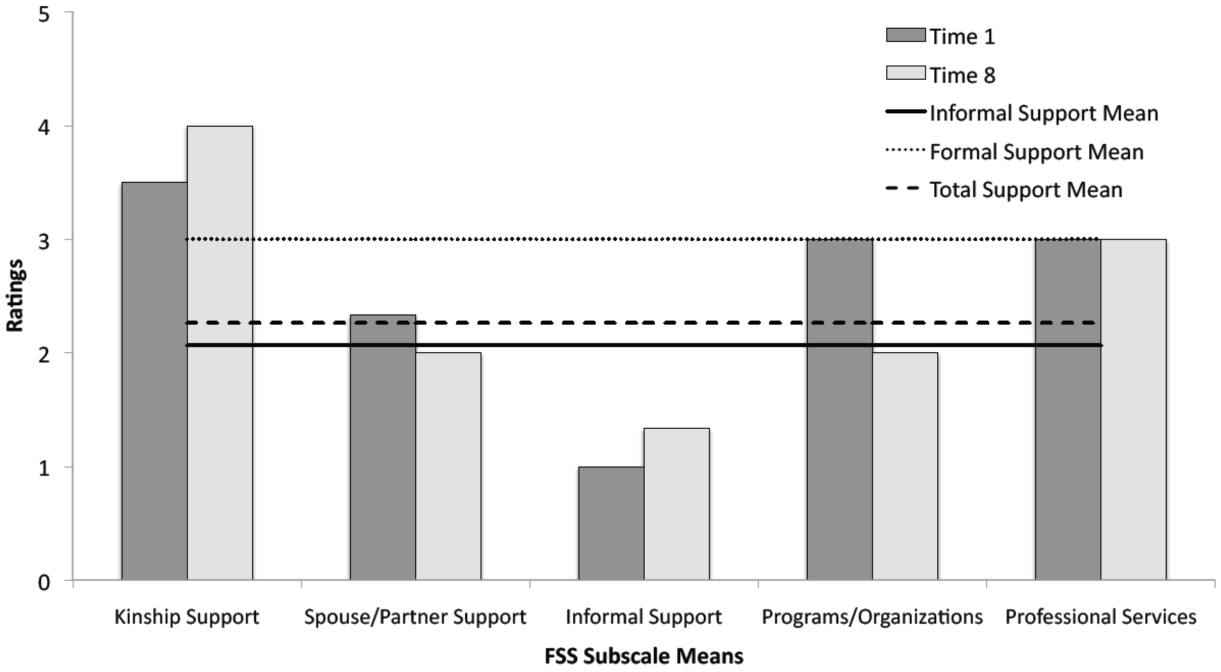

Figure 10. Family Support Scale (FSS) ratings for Case One: Jasmine. Ratings range on a six-point scale from *not applicable* (0) and *not at all helpful* (1) to *extremely helpful* (5), indicating higher scores equals greater social support.

members, and professionals to be the most helpful. This was reiterated in interviews and the services Jasmine listed on the Demographics Questionnaire (see Table 1). Jasmine indicated that her own parents and sister, her husband, her church minister (i.e., informal support), respite programs, and the psychoeducational support group (i.e., both a program/organization and professional services) to be the most helpful. Professional services that were listed as particularly beneficial included social workers (e.g., Coaching Families program and psychoeducational support group) and respite services, as well as teaching assistants. The rating scale indicated that Jasmine found many aspects of the psychoeducational support group to be helpful and supportive. The group was rated as *very helpful* for several aspects of the group, including learning how others deal with their problems, meeting people, being able to share feelings, and receiving support from other members. In contrast the support from her spouse's family is the least helpful. "They just don't understand about FASD. Nobody else in their family has any kind of disability at all. When he does something strange, they'll get mad, so we don't take him to [Clarence's parent's] at all" (22/T2/Line841).

Family quality of life. Jasmine answered questions regarding her family quality of life, or her satisfaction with her family life, in interviews and by completing the FQOL survey. Jasmine's mean rating on the FQOL survey was between *neither satisfied or dissatisfied* and *satisfied* before the intervention (*M* = 3.8) and *satisfied* after the intervention (*M* = 4). See Figure 11 for an overview of Jasmine's ratings on the FQOL, including total and subscale means. Jasmine's ratings on the FQOL indicated that she is most satisfied with her family interactions (*M* = 4.2) in comparison to the other subscales on the FQOL. She is least satisfied with the disability-related well-being, both before and after the study, were most closely rated by Jasmine to *satisfied*. Jasmine indicated she was *very satisfied* with several aspects: the support her family receives to relieve stress, friends or other who provide support, her family supports each other to accomplish goals, her family gets the medical and dental care when needed. Despite these positive elements in Jasmine's life, she is least satisfied with the support Logan receives to make friends, which was previously reported, along with difficulties with transportation and not having the time to pursue her own interests. Particularly, Jasmine wishes she was able to travel, but due to Logan's behaviour this is restricted:

> We used to go on trips and everything, but now, who's really going to watch Logan for a week or two? Mom might watch him for a couple of days, but she's not going to watch him for a week or two for us to go on a vacation, because he is a challenge.

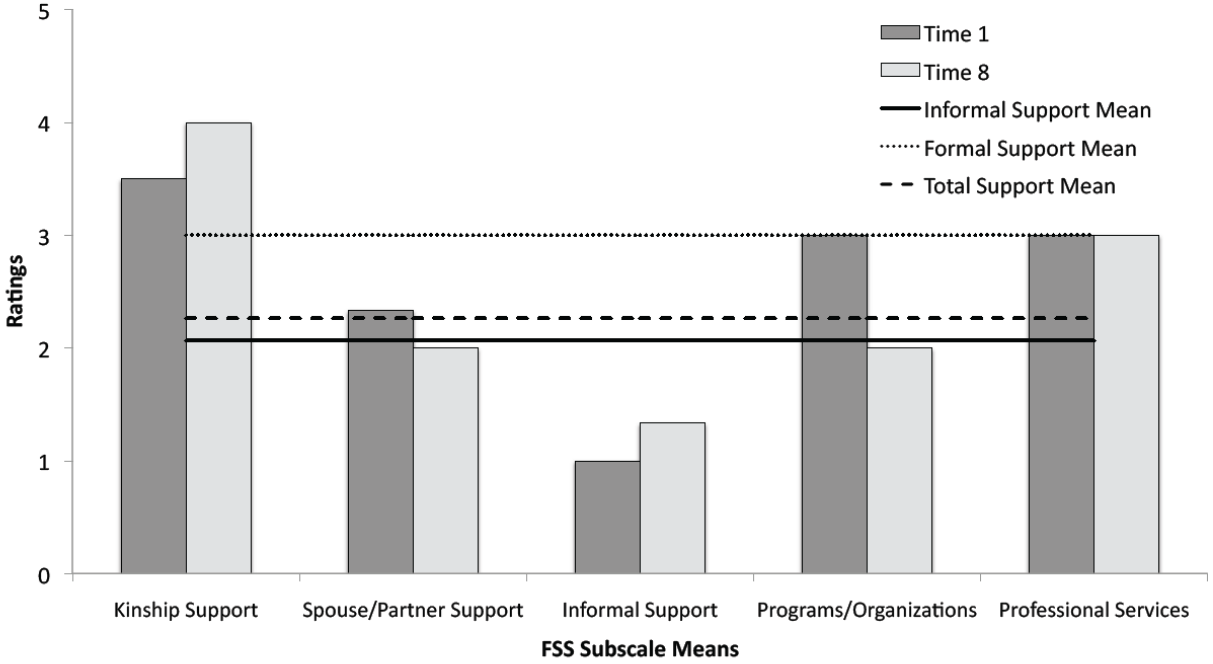

Figure 11. Family Quality of Life Scale (FQOL) ratings for Case One: Jasmine. Ratings range on a five-point scale from very dissatisfied (1) to very satisfied (5). Higher scores indicate higher satisfaction with life together with family.

(22/T2/Line789)

Jasmine feels it is too stressful to travel with Logan: "Just knowing that he will probably act out if we do go somewhere" (22/T2/Line832). He has difficulties listening, particularly when they are in larger crowds. "We would have had a better quality of life if he didn't have FASD, but what can you do" (22/T2/Line800). By the end of the study, Jasmine reported their quality of life had improved due to the support they were receiving through respite programs, as well as learning about different strategies and techniques through the psychoeducational support group.

Case two. The following sections provide information regarding Terry's experiences of prefigured or "a priori" categories, both from her daily experience and her specific experience of the psychoeducational support group: her experiences of stress, parental sense of competence, social support, and quality of life. Terry's broader experience is provided for context. A priori categories are presented individually, but are inevitably linked. Information was gathered from both qualitative (i.e., interviews, feedback forms, observations) and quantitative (i.e., questionnaires) sources.

Caregiver stress. Several areas of stress were identified for Terry, as well as aspects that help her deal with stress, both of which are discussed below. Information gathered from questionnaires, interviews, feedback forms, and observations revealed several sources of stress for Terry: lack of sleep, her son's extreme behaviour and constantly having to monitor his behaviour (i.e., PSI/SF [T1 and T8], interviews [T2 and T9], feedback forms [T3, T4, T5, T6, and T7], and observations [T4]), the newness of the experience (i.e., interviews [T2 and T9], feedback form [T3]), people trying to help that are unhelpful (i.e., interviews [T2 and T9], feedback form [T4]), and transitioning back to work (i.e., interview [T9], feedback form [T5]).

Terry's responses on the PSI/SF suggested Terry is experiences significant amounts of stress overall, as well, in comparison to other caregivers (see Figure 12 for Terry's ratings of stress on the PSI/SF). On the PSI/SF, Terry's responses indicated clinically elevated levels on the Parent-Child Dysfunctional Interactions and Difficult Child factors, as well as on the Total Stress score, with scores at or above the 90th percentile, both on pre- and post-intervention measures. Terry's scores on the Parental Distress factor fell at the 55th percentile pre-intervention and at the 82nd percentile after the intervention was completed, in comparison to the normative sample. This is congruent with Terry's report that her stress had increased over the course of the project, particularly a few weeks before the end of the project (i.e., T6 to T9), due to her son's negative behaviour.

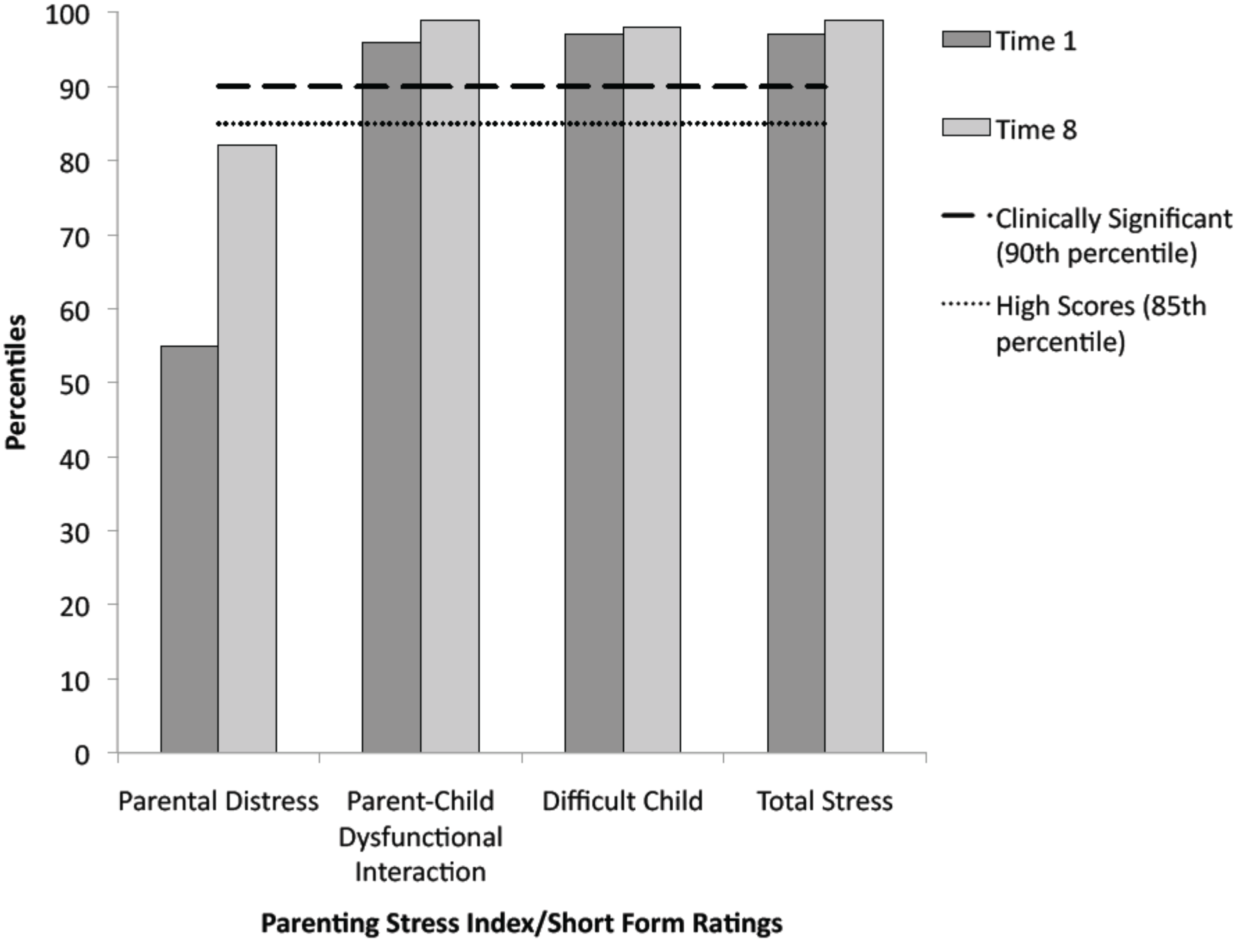

Figure 12. Percentiles of Parenting Stress Index/Short Form (PSI/SF) ratings for Case Two: Terry.

When asked about her high scores on the PSI/SF, Terry indicated she does sometimes feel that her stress is clinically elevated but was a bit surprised. Instead she indicated she felt her stress to be at the high end of the average range, but not in the clinically significant range compared to other parents. She reported that when she talks with some other mothers she is surprised at how they are able to talk and reason with their children, and that "their kids are a

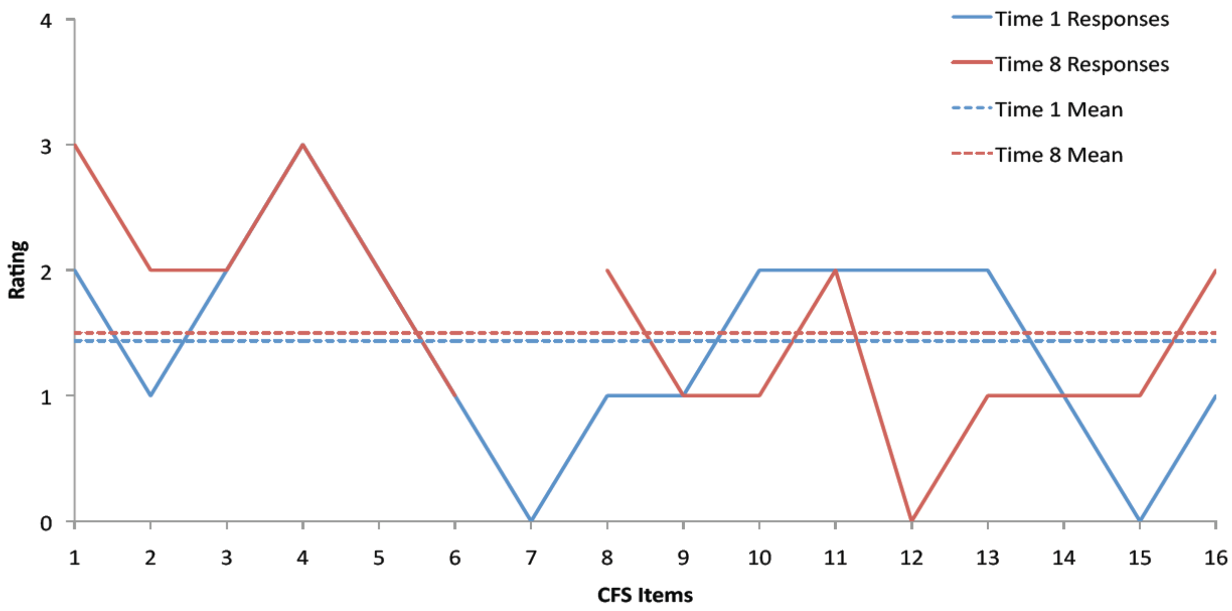

Figure 13. Coaching Families FASD Stress Scale (CFS) ratings for Case Two: Terry. Ratings range on a five-point scale from *never* (0) to *constantly* (4), indicating higher scores equals greater stress levels.

little bit more reasonable" (23/T9/Line1976). She described her son as being hard to "settle down" (23/T9/Line1978).

Despite the CFS indicating somewhat elevated levels of stress for Terry, Terry's perception of her own level of stress may be more adequately reflected by her responses on this measure (see Appendix H for CFS questions). Overall, Terry's ratings on the CFS, both before and after the intervention, fell between *rarely* and *sometimes* when answering questions about her level of stress ($M = 1.4$, $M = 1.5$, respectively; see Figure 13). Both before and after the intervention on the CFS, Terry indicated she is frequently worried that daily life will get harder as he gets older. This was reiterated in interviews with Terry, as she is stressed that his behaviour would continue to escalate: "You see this aggressive behaviour in him, and you just worry, 'Will that go away?' And hopefully it will" (23/T9/Line2241). Terry's stress increased over the time of the project, as a result of his behaviour. Shortly after Terry and her husband had adopted their son, things started getting "fairly bad" (23/T2/Line634). Their son had started reverting back to behaviours in which he had previously progressed. They attempted to access support in the community, including CASA and Coaching Families, but were faced with waiting lists. They attempted to access a youth worker for their son, a service he had been provided in his previous community, but were denied. Shortly after they had been denied a youth work, they had another rough weekend. He was having a "fit" (23/T2/Line656), including scratching Terry and climbing on railings at unsafe heights, and Terry once again asked for a youth worker. She had videotaped with her phone some of the instances, and included that information in her request. Terry and her husband were also having difficulties with behaviour management, particularly using punishment for excessive swearing, as well as trying to ignore inappropriate behaviours. With these difficulties, their adoption worker put a behavioural consultant in place to work on behaviour management. After the intervention, Terry also indicated that she is frequently tired and exhausted. Terry explains, "In January, it got rough. He was waking up almost every night. We weren't getting full nights sleep. He was acting up more and more" (23/T2/Line524). Tyson's extreme behaviours had decreased over the course of the study, but the "outbursts, name calling, and general rudeness" (23/T6/Line7) continued to increase. "There's also been some incidents at the school with swearing and stealing, resulting in a couple extra meetings there" (23/T6/Line9). She elaborated, "He just won't do anything that's requested" (23/T9/Line533). Furthermore:

> Sometimes he'll flop on the floor. He'll yell. When he gets up into his room, he's kicking

> the door…There were times when it would be an hour or two, in his room, yelling and screaming, kicking the doors. Sometimes we would be in the room with him, if he was calm enough. Sometimes we'd be outside the room. (23/T9/Line537)

It was not just the outbursts that stressed Terry, but not knowing when they were going to occur. "You just never know what's going to set him off. We're getting used to it. So that kind of helps reduce the stress level, when you just get used to it. But again, it's always that ebb and flow" (23/T9/Line496). As Terry describes, it is this "continual little bit of stress that's there" of not knowing what, if anything, is going to set him off. The combination of this uncertainty with the having difficulty of completing weekly tasks, like as Terry put it, "when things aren't getting done that need to get done" (23/T9/Line1900), were compounded stressors for Terry.

Terry's husband tries to help her when she is stressed, but unfortunately it only exacerbates the stress she is experiencing, as indicated by interviews (i.e., T2 and T9) and feedback form (i.e., T4). Instead, when she is experiencing stress in response to a specific event, she would prefer to be left alone for a few minutes.

> He's funny. He likes to help. He's a people pleaser, so he'll try and help me. But I'm an introvert. If I'm stress leave me alone for 15 minutes! Quit trying to help me, and quit trying to say, 'Are you ok?' (23/T9/Line1042)

At times, Terry also asked Tyson to give her space when she really needed it.

Tyson's extreme behaviour, outbursts, and the need for his behaviour to be closely monitored, in combination with Terry loosing sleep and having to navigate her husband's attempts to help, are all adding to Terry's stress. Moreover, parenting is a new experience for Terry, and she was in the process of transitioning back to work. At the time of the study, Terry had experienced parenting for less than one year. This is an added complex layer to Terry's stress, which she briefly touches upon:

> I think a lot of it is the newness of it too. A lot of other parents, they've been doing this for a while, or they have multiples so they know how to deal with their kids. I think that kind of plays into it a little bit. (23/T9/Line2025)

Trying to balance all of her activities was an added pressure for her, as it is for many parents:

> You hear about mother's talking about when they feel guilty because they're not doing a great job at work, and they're not doing a great job at home. But there are times where, yeah, I just don't feel like I'm really giving work my all. (23/T2/Line1848)

There are several services that Terry indicated she found helpful for lowering her stress and dealing with her son's behaviour. Terry listed several services, including the psychoeducational support group, the Coaching Families program, and pediatrician. In addition to services, Terry also indicated taking time for herself and having a break, with the assistance of respite services, which allows her to manage her stress.

In addition to having time to herself, Terry appears to also benefit from services that also provides some guidance or information for Terry to gain from as well. Terry reported that the psychoeducational support group somewhat helped reduce her stress on the rating scale of the intervention components, in interviews, and feedback forms. Terry indicated on the rating scale that the group was between *somewhat helpful* and *very helpful* for "feeling less stressed as a parent" (23/T8/Question12h). Terry indicated the group helped reduce her stress because "it gives you that venue to talk, and to hear other people's stories, and to know you're not alone. That just helps so much" (23/T9/Line2356). This was reiterated in some of the benefits of Terry's attendance of the group discussed earlier, including making connections and envisioning a positive future for her son. Terry indicated on feedback forms that her involvement in the

Coaching Families program also helped her manage her stress. For example, "The Coaching Families mentor helped with some strategies and was a general outlet to discuss my frustrations" (23/T6/FeedbackForm). Terry also indicated her son's pediatrician was an area of support for her. The pediatrician helped by listening to what Terry was experiencing, and giving advice as needed. "Just kind of listening to us, kind of telling us what's normal, what isn't. Either validating or giving different suggestions here and there" (23/T9/Line1479). The pediatrician discussed with Terry some of the behaviour that Tyson was experiencing and attempted to put them in context, particularly near the end of the project when school was almost finished.

In addition to the services that Terry and her family have accessed and that Terry have found helpful, Terry also found having a few minutes alone the most helpful strategy she used at home for helping her stress. Terry's stress increased when she did not get enough down time. That is why respite services were so important for Terry, "We just need to make time for it. And we just knew we were getting stressed and frustrated enough that, okay, we needed that break" (23/T9/Line505). Even if the break allows Terry and her husband to do complete day-to-day chores, it helps Terry to feel a bit relieved.

Finally, Terry reported she found talking with her sister-in-law helpful. Her sister-in-law often provided suggestions regarding services in the community, including the services offered at the Glenrose Rehabilitation Hospital. Despite not knowing about Tyson's FASD diagnosis, Terry reported that her sister-in-law often listened to what she and her son were experiencing.

Caregiver sense of competence. Information about Terry's feelings of parental sense of competence, and her related experience of the psychoeducational support group, was gathered primarily through interviews and PSOC questionnaire. Interviews indicated six themes related to Terry's feelings of parental competence: her acceptance and willingness to learn, willingness to dedicate time, adapting as needed, preventing behaviours from escalating, and feeling knowledgeable as a parent.

Despite the newness of Terry's experience of being a parent for Tyson, Terry indicated there was several reasons why she felt competence and even confident as a parent. At times she worries whether or not she is doing the "right thing" (23/T9/Line2054), but overall she feels confident: "I'm reasonably confident that [my husband] and I are doing the right things, and that does help" (23/T9/Line2105). Terry further explains:

> I think overall [my husband] and I doing the best we can, and I do think we're probably better than a lot of parents out there. So I don't really worry too much about that. I do worry about trying to figure out the right thing to do, or the thing that will work, like revamping our reward system. (23/T9/Line372)

Terry reports her confidence comes from several sources. Her acceptance of Tyson and his diagnoses, as well as her willingness to learn how to help him, are areas of strength for her. Taking the time to learn and adapt as needed can take time, and her dedication to taking whatever time is needed to help him also helps with Terry's feelings of self-efficacy. Terry reports:

> Instead of trying to force him to conform to what we want, we try to work with him and his behaviours… We are willing to dedicate that time to him. I think the danger in life is that you get too busy. (23/T2/Line618)

Terry feels most confident when she is successful in dealing with Tyson's behaviour, particularly when she prevents his behaviour from escalating, and seeing Tyson's behaviour progress: "He's recognizing that he was rude. He's coming back and saying sorry. You know, those little things – I know we're starting to connect as a family" (23/T2/Line1143).

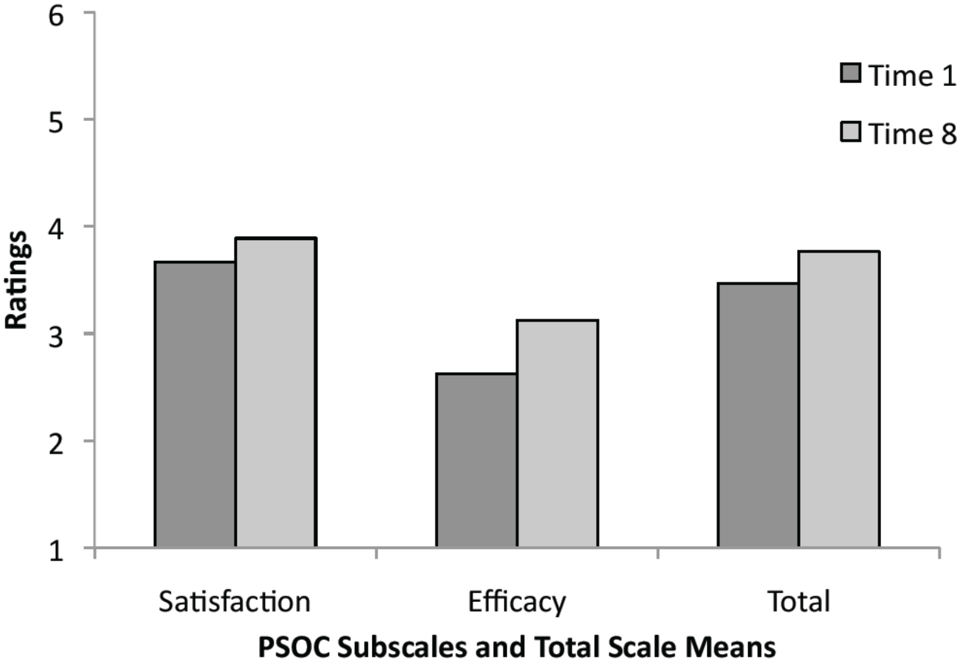

Figure 14. Parenting Sense of Competence Scale (PSOC) ratings for Case Two: Terry. Ratings range on a six-point Likert scale from *strongly disagree* (1) to *strongly agree* (6), indicating lower scores equals greater self-efficacy.

Terry's responses on the PSOC reflected the level of confidence she indicated in interviews (see Appendix I for the questions on the PSOC; see Figure 14 for visualization of the means for Terry's responses on the PSOC). Overall, Terry's total score on the PSOC was between *disagree* and *agree*, both before (M = 3.47) and after (M = 3.76) the intervention, for such questions as "I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot." However, Terry's responses on items related to her self-efficacy of being a parent were slightly lower than her ratings of items related to her satisfaction as a parent, suggesting she may feel more confident than satisfied as a parent. This is congruent with information gathered from interview and feedback form sources.

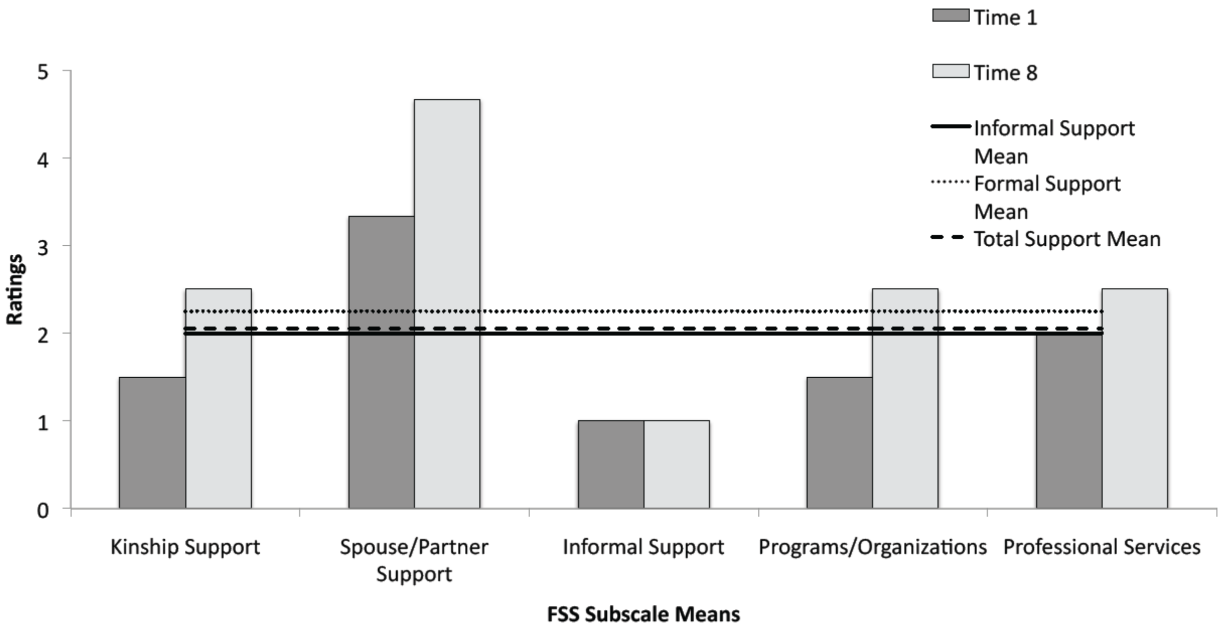

Figure 15. Family Support Scale (FSS) ratings for Case Two: Terry. Ratings range on a six-point scale from *not applicable* (0) and *not at all helpful* (1) to *extremely helpful* (5), indicating higher scores equals greater social support.

Family support. Information about Terry's social support, including the psychoeducational support, was gathered through interviews, feedback forms, and the FSS. Terry's ratings on the FSS can be found in Figure 15. Terry's social support was mapped onto three of the five areas assessed by the FSS (see Figure 19): spouse/partner, programs/ organizations, and professional support. Overall, Terry's responses on the FSS indicate her total social support to be closely ranked to *sometimes helpful* (overall $M = 2.05$). Terry received slightly better support from professional services ($M = 2.25$) than from informal sources (e.g., kinship, spouse, informal, and program/organization support; $M = 2.00$) overall. Overall, Terry rated the informal support she received as *somewhat helpful* and the professional support slightly she received in between *somewhat helpful* and *generally helpful*. Specific items on the FSS indicate she finds the support she receives from her spouse's kin (i.e., sister-in-law), spouse, pediatrician, friends, school, and professionals to be the most helpful, which is consistent with information gathered through interviews and on the rating scale of intervention components. The FSS results reiterate the important support she received from her sister-in-law, which was previously discussed, as well as professional services (i.e., psychoeducational support group, Coaching Families program, pediatrician, and respite services). When asked "How supported did you feel in this group?" Terry rated her experience in the psychoeducational support group as *very supported* (23/T8/Question13). She rated the group as very helpful for several aspects: finding out how others deal with their problems, getting a chance to meet people with similar problems, sharing feelings with other group members, getting support from other members, learning practical solutions to everyday problems, feeling less isolated and alone, gathering information, learning where to find information, learning strategies, and sharing successes and challenges. In contrast, Terry finds the support she receives from her co-worker, as *not at all helpful*, probably due to the contract position she currently holds and the stress associated with transitioning back to the work environment, and trying to juggle the demands of her work schedule with things that have to be done at home.

Family quality of life. Terry answered questions regarding her family quality of life, or her satisfaction with her family life, in interviews and by completing the FQOL survey. Terry's mean rating on the FQOL survey was between *neither satisfied or dissatisfied* and *satisfied* both before (M = 3.44) and after (M = 3.68) the intervention. See Figure 16 for an overview of Terry's ratings on the FQOL. Terry's ratings on the FQOL indicated she is most satisfied with her physical and material well-being (i.e., material resources; M = 4.6 pre-intervention and M = 4.4

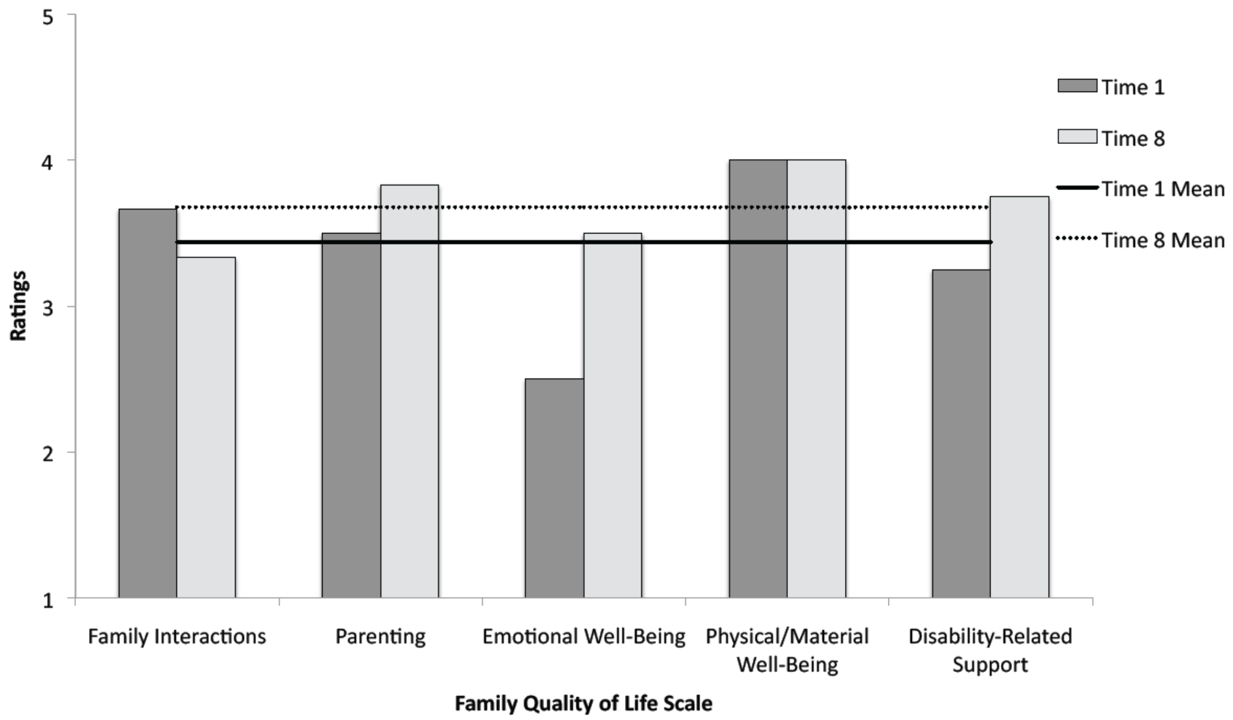

Figure 16. Family Quality of Life Scale (FQOL) ratings for Case Two: Terry. Ratings range on a five-point scale from very dissatisfied (1) to very satisfied (5). Higher scores indicate higher satisfaction with life together with family.

post-intervention), and least satisfied with her emotional well-being (*M* = 3.0 pre-intervention and *M* = 3.5 post-intervention), particularly prior to the beginning of the intervention when she indicated she is *neither satisfied or dissatisfied* with her emotional well-being.

In interviews with Terry, she indicated she felt her quality of life had greatly increased since the adoption of Tyson, not only because she was now a parent, but also because it had changed her relationship with her husband.

> I think [my husband] and I’s relationship is stronger…I think we were largely stagnating as a couple. I think we knew something was missing. We’ve got this child that we love,

> we're communicating better, we're doing more things together. Yea, we have some stressful moment, but we had stressful moments before too, it's just a slightly different kind of stress. (23/T2/Line1334)

Terry later reiterates that without Tyson "we'd still be pretty empty" (23/T9/Line126).

Case three. The following sections provide information regarding Janelle's experiences, both her general experiences and specific experiences of the psychoeducational support group, related to the predetermined or "a priori" categories previously discussed: stress, parental sense of competence, social support, and quality of life. Janelle's broader experiences are provided for contextual information for Janelle's experience of the group. Although the a priori factors are presented separately, many aspects are linked and some links are provided below. Information was gathered from both qualitative (i.e., interviews, feedback forms, observations) and quantitative (i.e., questionnaires) sources.

Caregiver stress. Several areas of stress, and aspects that help with stress, were identified for Janelle. Information gathered from questionnaires, interviews, feedback forms, and observations revealed several sources of stress for Janelle: dealing with the school system (i.e., interviews [T2 and T9]), experiencing side effects due to medication (i.e., feedback form [T6 and T7]), judgmental attitudes (i.e., interview [T2], observations [T4]), constantly monitoring and extreme behaviours (i.e., PSI/SF, interviews [T2 and T9]) as well as appointments and maintaining employment (i.e., PSI/SF [T8], CFS [T8], interviews [T2 and T9]).

Janelle's responses on the PSI/SF and the CFS both suggested Janelle is experiencing significant amount of stress overall compared to other parents (see Figure 17 for Janelle's percentiles on the PSI/SF; see Figure 18 for Janelle's ratings on the CFS). On the PSI/SF after the intervention, Janelle's responses indicated "clinically significant" (at or above the 90th

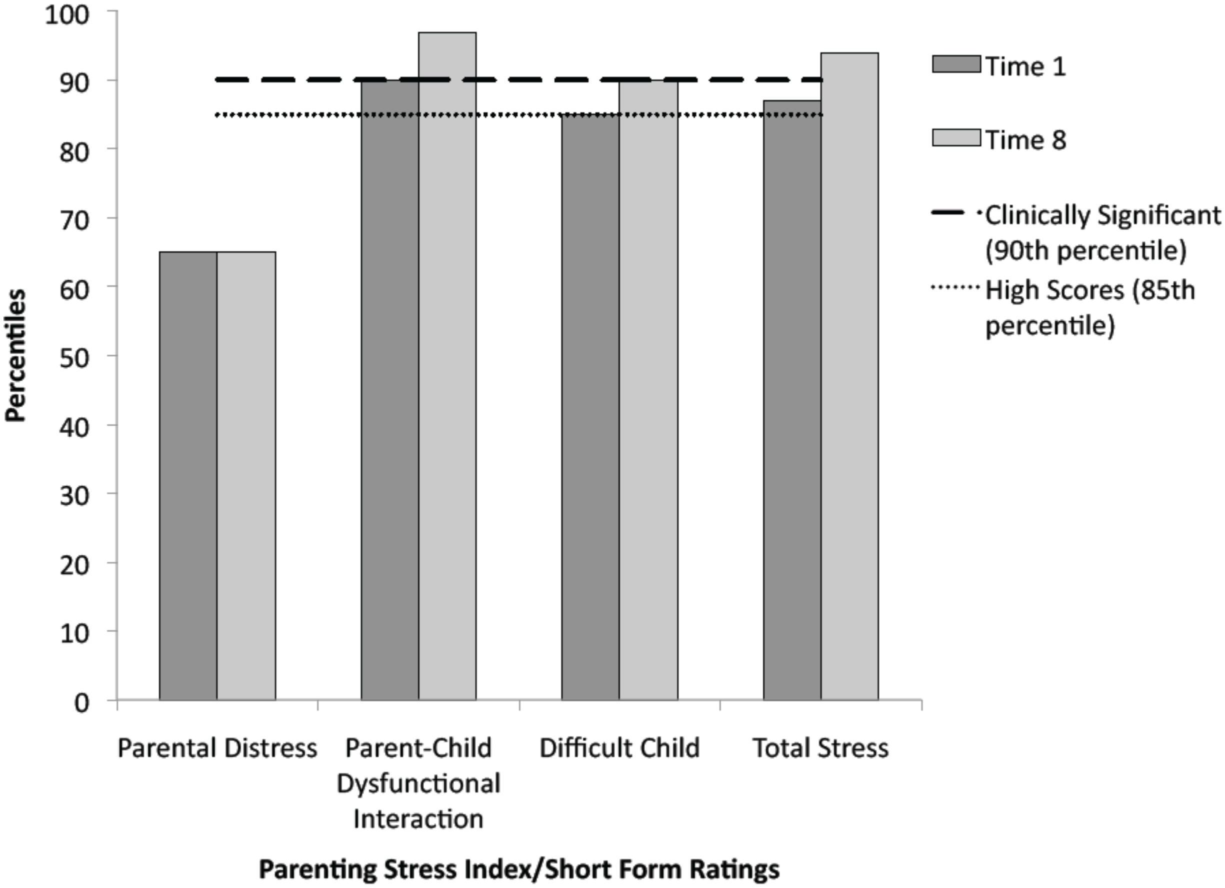

Figure 17. Percentiles of Parenting Stress Index/Short Form (PSI/SF) scale ratings by Case Three: Janelle.

percentile) levels of stress on two out of the three measured factors (Parent-Child Dysfunctional Interactions and Difficult Child) as well as on the Total Stress score. Before the intervention, Janelle's stress fell in the "high" range (at or above the 85th percentile) for two out of the three measured factors (Parent-Child Dysfunctional Interactions and Difficult Child) as well as on the Total Score.

Throughout the course of the study, as shown by interviews (i.e., T2 and T9),

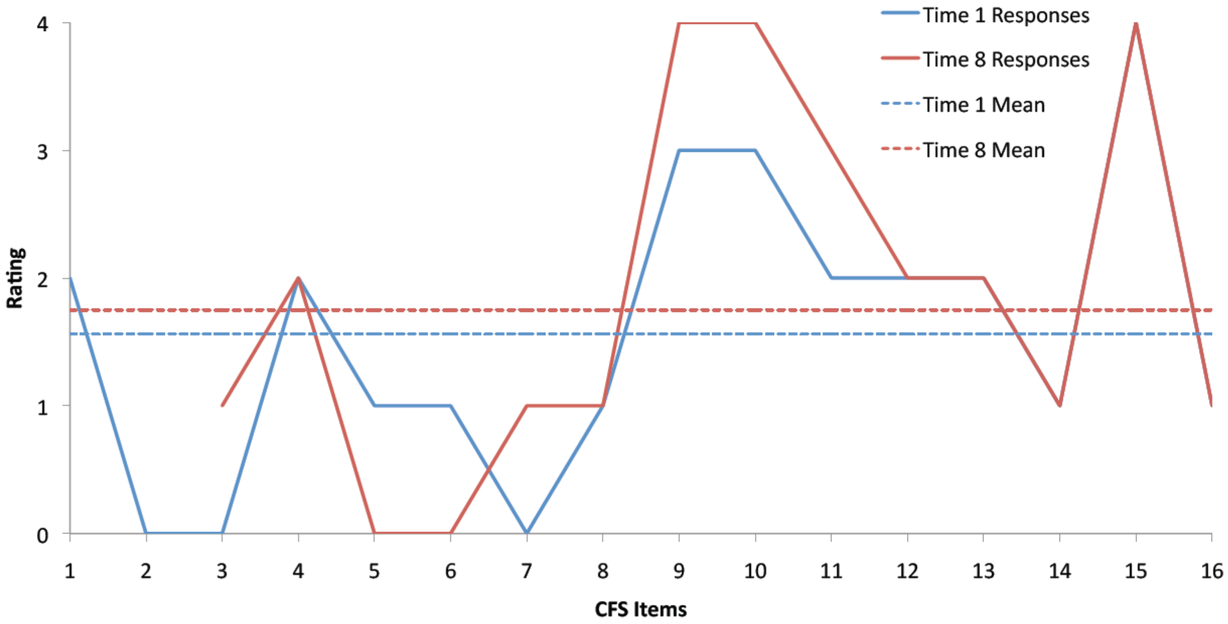

Figure 18. Coaching Families FASD Stress Scale (CFS) ratings for Case Three: Janelle. Ratings range on a five-point scale from *never* (0) to *constantly* (4), indicating higher scores equals greater stress levels.

Janelle had a strained relationship with Sarah's school, which was added stress for her. Janelle felt that Sarah's teacher was not options and there are A, B, and C, and C is the medication, I want to try A and B first" (25/T2/Line287). Furthermore, Janelle had enrolled Sarah in a school that she felt best suited her needs, but meant that she had to drive Sarah to the school across town every morning, when Janelle's car broke down that was another added layer of stress.

Janelle indicated that Sarah's behaviour has fluctuated over the three years that she has been in her care. Sarah often becomes upset and angry, and has in the past engaged in unsafe behaviour, but she does so less frequently than she did a year ago when Sarah and Janelle were dealing with the courts as part of the adoption process. Janelle described her episodes during this time as very intense:

> It would be a complete melt down. She would be completely out of control. She will scream. She will kick. She will also peep and poop her pants…She's out to destroy something. She will destroy her room, scream horrible things. She will just scream and you can't make her stop…It's like a blood curdling, someone is killing me scream. (25/T2/Line759).

In the past, Sarah's screaming episodes could go on for hours. Janelle indicated there was often a small window prior to these episodes where she could sometimes snap her out of it: "You're trying to grab her before she's gone…It's a complete disassociation, really." (25/T2/Line810). However, Sarah has been working with a therapist that is helping to address her symptoms related to her diagnosis of Post-Traumatic Stress Disorder, and Sarah is now doing better at expressing and trying to explain her feelings using labels before becoming extremely upset.

Despite Sarah's progress with extreme behaviour at home, Janelle reported that Sarah continues to struggle with her behaviour at school. When Janelle first started caring for Sarah, Sarah's teachers often called her to pick her up from school. Janelle indicate, "She wouldn't get off the floor, she spat at teachers, and she hit herself." (25/T2/Line512). Janelle thought Sarah's behaviour at school was at least partly linked to the unrealistic expectations that had for her, for example, to sit in her desk for long periods of time. Janelle often met with the school with her Coaching Families mentor to help deal with her behaviour and create realistic expectations and goals.

Sarah had been taking medication to help her with managing her angry outbursts. Sarah had been on medication approximately two years before, and Janelle believe it had a negative effect on her: "It made her either extremely incoherent… or she was very irritable"

(25/T2/Line350). While Sarah had been living with her biological mother, she had taken medication for her inattention and impulsivity (i.e., Dexedrine and Clonidine). When she began living with Janelle, Sarah saw a new doctor that began to reevaluate the medication she was taking. At that time, Sarah's impulsive symptoms had largely decreased, and Janelle made the decision to take Sarah off the medication. Overall, Janelle felt the medication actually made her behaviour worse, not better: "It made her extremely incoherent or she was very irritable." (25/T2/Line350). Janelle had spent a lot of time with the doctor weaning Sarah off the medication; however, during the course of the study Sarah was once again place on medication due to her difficulties with attention and functioning in the classroom. Sarah's teacher suggested to Janelle that Sarah go back on her medication. At the beginning of the study, Janelle indicated she first wanted some additional strategies to be tried first before resorting to medication. By the end of the study, Sarah had been on several types of medication, but had not taken medication for three weeks. Janelle had reported that it had been a rough copy of months; unfortunately, the medication caused many side effects. Sarah had not been sleeping because of the medication, and again Janelle reported that her behaviour had again gotten worse. Her difficulties with sleeping affected how both Sarah and Janelle functioned during the day: "It made our life worse not better" (25/T9/Line1419). Sarah had also started to engage in behaviour that Janelle had not seen in awhile, including some extreme behaviours. Monitoring these extreme behaviours once more was an additional source of stress. Janelle was hopeful that when school started in the fall her new teachers would be able to get her back on track and that the strategies they would use would prevent her from needing medication.

Finally, throughout the course of the study, Janelle had been let go of her job and she was particular about what jobs she could apply for due to the large number of appointments that she had to attend with Sarah:

> I am really careful about what I'm looking for, because I can't go sign up for a Monday to Friday, 8 to 4 job. Who's going to take her to her appointments? Who is going to take her to the dietician, who's going to take her to Dreamcatcher? How am I going to go to the support group? (25/T9/Line1518)

At one point she felt so financial strained that she approached Alberta Human Services to receive some extra support, but was turned down. Janelle loosing her job as well as her car breaking were large sources of stress that greatly impacted her daily living. This is reflected in Janelle's ratings both on the PSI/SF and CFS.

Despite Janelle's multiple sources of stress, several supports help her to deal with stress, including participating the psychoeducational support group and Coaching Families program. Both sources in and outside of the group that help Janelle are discussed.

For Janelle it arose that social support was a particularly important for Janelle to deal with stress. This was evident both in the benefits she received through the psychoeducational support group as well as the key aspects she indicated helped her the most with stress. Specifically, when Janelle is very stressed she indicated she will call a friend or her mother. Additionally, Janelle indicated that she benefited from talking with other members of the psychoeducational support group, and even preferred to have more opportunities for discussions rather than attending information sessions. Furthermore, Janelle indicated she appreciated the support she received through Coaching Families for advocating, educating, and working with the school system, particularly when the school was encouraging the use of medication to help with Sarah's symptoms of inattention. Janelle's stress was also alleviated when she learned that two teachers that had previously taught Sarah would be returning. Janelle's social support is discussed in more detail below. Janelle rated the group as between *somewhat helpful* and *very helpful* for helping to reduce her stress on the rating scale.

Janelle indicated one additional way that her stress levels are alleviated. This included becoming aware of events for children with special needs. For example, K-Days, a Midway and music event in Edmonton, provides one day where it is only open for children with special needs. This allows Janelle to take Sarah without the fear of judgment from other people, particularly since she has received many negative and judgmental comments from others due to Sarah's sometimes-extreme behaviour. However, at these events Janelle describes, "No one's looking. You just kind of walk by, smile, nod. If only it was like that wherever you went. Just that common understanding" (25/T2/Line1058). Janelle indicated having similar events would be helpful.

Caregiver sense of competence. Information about Janelle's feelings of parental sense of competence was gathered primarily through interviews and PSOC questionnaire. Interviews indicated five themes related to Janelle's feelings of parental competence, both inside and outside the psychoeducational group, and questionnaire data provided additional information about Janelle's levels of perceived competence. The five themes were as follows: understanding, willingness to learn, patience, parental knowledge and strategies, and advocacy skills. Janelle's understanding, willingness to learn, and patience were all identified by Janelle to be her strengths as a parent. Additionally, Janelle also felt very competent during one particularly episode where Janelle had the opportunity to meet with school staff and advocate for Sarah's needs:

> The times when I've been able to stand up for Sarah, like going to the school and dealing with those kinds of things. That makes me feel competent. I don't let things rest like that. I'm just trying to make it better for Sarah. (25/T2/Line1250)

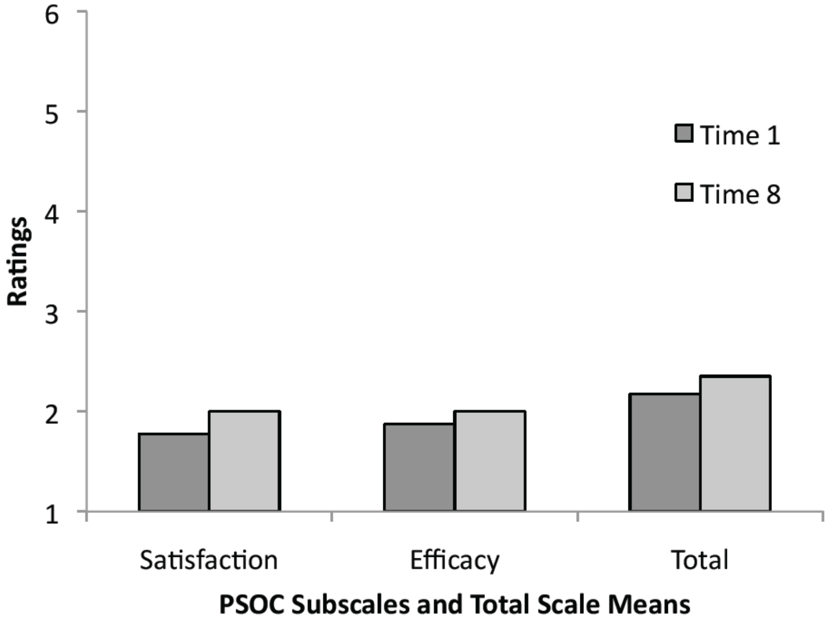

Figure 19. Parenting Sense of Competence Scale (PSOC) ratings for Case Three: Janelle. Ratings range on a six-point Likert scale from *strongly disagree* (1) to *strongly agree* (6), indicating lower scores equals greater self-efficacy

These aspects of herself help to improve her feelings of self-efficacy, and help her to feel successful as a parent. Additionally, Janelle has a particular interest in parenting and learning about effective parenting strategies:

> I'm always up to try something. If it doesn't work, it doesn't work, but it doesn't hurt to try, right? I think you can always learn and grow and be better at everything, right? Parenting included. I think you have to have that attitude, you have to be changing it up and bringing fresh things to the table. (25/T2/Line1336)

Janelle's high sense of competence was reflected in her ratings on the PSOC (see Figure 19). Overall, Janelle's satisfaction in her parenting role, her feelings of efficacy related to

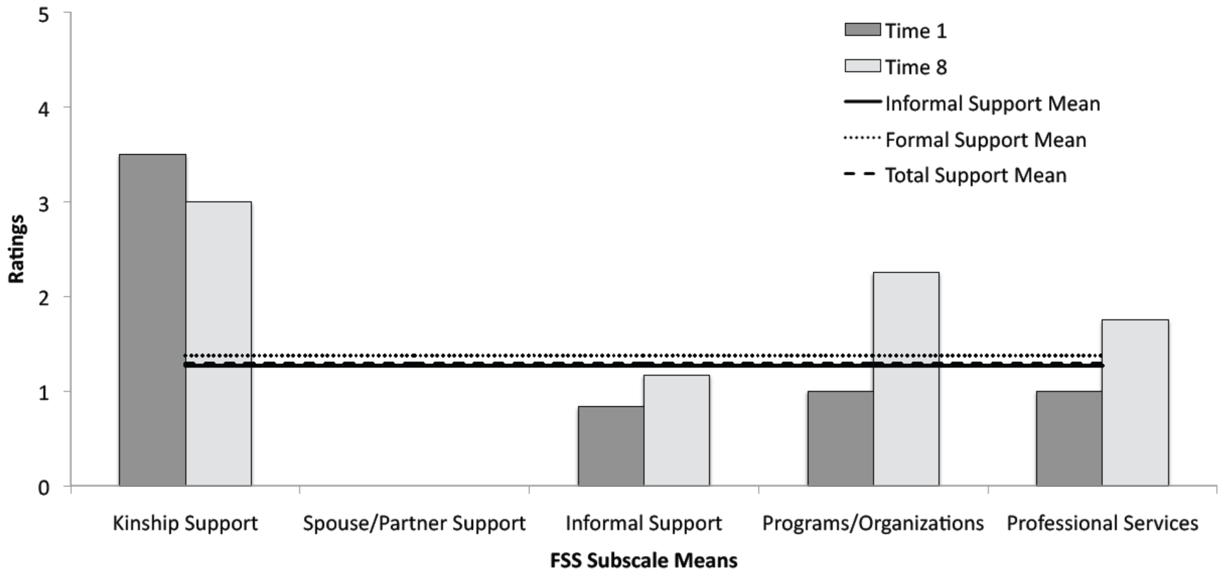

Figure 20. Family Support Scale (FSS) ratings for Case Three: Janelle. Ratings range on a six-point scale from *not applicable* (0) and *not at all helpful* (1) to *extremely helpful* (5), indicating higher scores equals greater social support.

parenting, and her total parenting sense of competence ratings around the rating *strongly disagree* to such statements as "Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age" or "Being a parent makes me tense and anxious" (see Appendix I for the questions on the PSOC). "I feel successful most of the time. Whenever Sarah is happy, that makes me feel successful" (25/T2/Line750).

Family support. Information about Janelle's social support, including within the psychoeducational support group, was gathered through interviews, feedback forms, and the FSS. Janelle's ratings on the FSS can be found in Figure 20. Janelle's social support was mapped onto four of the five areas assessed by the FSS. The remaining areas are kinship (i.e., parents), informal (i.e., friends), programs/organizations (i.e., psychoeducational support group), and professional (i.e., psychoeducational support group, Coaching Families program, Dreamcatcher Association, and the school system and staff) support. Overall, Janelle's responses on the FSS indicate her total social support to be ranked between *not at all helpful* and *sometimes helpful* (*M* = 1.29); however, since Janelle is a lone parent the fifth area related to spouse/partner support was not necessarily applicable for her, and therefore this may have decreased her overall scores for social support. Janelle's ratings indicated she received relatively similar support from formal services and professionals (*M* = 1.37) and informal (e.g., kinship, informal, and program/organization support; *M* = 1.27) services. Overall, information from the FSS indicated Janelle's family is the most supportive for her, which was reiterated by specific items on the FSS (i.e., parents and relatives). Additionally, Janelle rated her friends as particularly supportive. Finally, Janelle rated school staff, professional helpers (e.g., therapists, social workers), and professional programs (e.g., psychoeducational support group, Coaching Families program) as supportive, particularly at the end of the study. This reiterated information gathered from Janelle in interviews and feedback forms. On the rating scale of intervention components, Janelle also rated that psychoeducational group as *very supported* when asked "How supported did you feel in this group?" (25/T8/Question13). Additionally, a helpful aspect of the group for Janelle was receiving support from other members of the group, which she rated as *very helpful*.

Family quality of life. Janelle answered questions regarding her satisfaction with her family life, both in interviews and by completing the FQOL survey (see Figure 33). Janelle's mean rating on the FQOL survey, both before and after the intervention, was between *satisfied* and *very satisfied* (*M* = 4.12, *M* = 4.32, respectively), suggesting a high quality of life. Janelle's

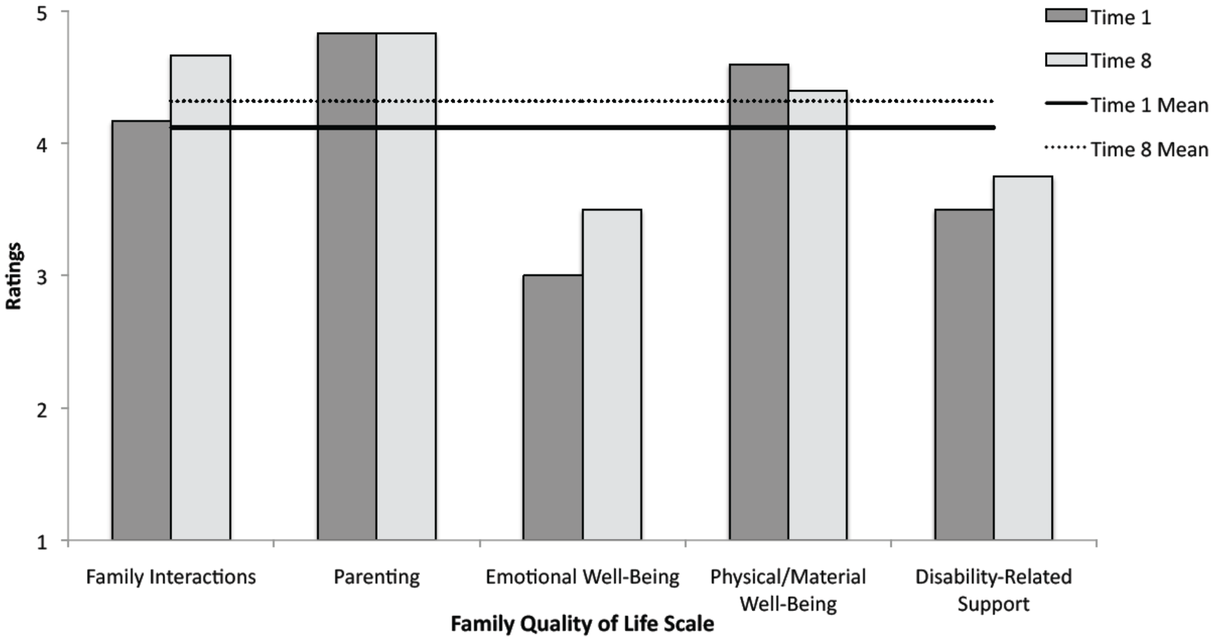

Figure 21. Family Quality of Life Scale (FQOL) ratings for Case Three: Janelle. Ratings range on a five-point scale from very dissatisfied (1) to very satisfied (5). Higher scores indicate higher satisfaction with life together with family.

ratings on the Parenting subscale were rated highest both before and after the intervention. This subscale measures Janelle's satisfaction of the family processes between family members that contribute to a subjective sense of family well-being (Hoffman et al., 2006). This subscale includes items such as "Family members help the children learn to be independent" and "Adults in my family teach the children to make good decisions." Janelle was least satisfied with her emotional well-being, which she rated as *neither satisfied or dissatisfied* prior to the study (*M* = 3.0) and between *neither* and *satisfied* after the study (*M* = 3.5).

When asked about how becoming a parent had influenced her quality of life, her response reflected her high ratings on the FSS, as well as her satisfaction ratings on the PSOC:

> It's changed my whole life. It's not a good thing or bad thing. My life raising Sarah is a completely different life than without. I think that it takes a lot to be a parent, and it takes 100 times more to parent a child like Sarah. Especially for someone like me, any day I could have just quit…But now that I have her, I wouldn't trade her for the world. There is nothing that anyone could say that would make me change that. But I think it's definitely a learning thing, and I think it gets easier. Some days are really easy, but you just have to know that that's not going to be everyday. Just saver those days and hope that there's more. (25/T2/Line1495).

Research Question B: Individual Experiences, including Benefits and Barriers

The goal of the analysis was to determine themes related to caregivers' experiences of the psychoeducational support group. Constant comparison analysis was conducted on qualitative data: interviews, observations, and feedback forms. Ratings of session components were also reviewed and compared to qualitative codes. Reviews of qualitative data began following interviews and during transcription. Coding memos were kept throughout the process, and themes were generated from initial codes and redefined over time after being refined, peer reviewed, and member checked. The following are themes that emerged through analysis. Excerpts from data sources are provided in order to provide support for the reader.

Case one. Several aspects of the psychoeducational support group were identified by Jasmine to be both benefits and barriers for attending the group. Benefits were conceptualized as elements of the group that the participant felt to be helpful, whereas barriers were unhelpful aspects that at times hindered her ability to have a positive experience of the group.

Benefits. Through interviews and feedback forms, several benefits of the psychoeducational support group were identified for Jasmine. Benefit codes were derived largely from interviews, and commonalities across qualitative data. Four benefits were established: (a) Shifting Perspectives, (b) Differentiating Developmentally-Appropriate Behaviour, (c) Learning from Others: "A Sounding Board" and (d) Access to Resources. Jasmine attended all the psychoeducational support group sessions conducted throughout the study.

Shifting perspectives. Jasmine frequently stated across interviews and feedback forms that the group helped her to focus on the positive attributes of her son, and the things that were going well, rather than focusing on what needed to be changed or improved. Jasmine indicated in on an early feedback form, "It [has] helped me see the positive things that he's done over the last few months, and to appreciate his personality" (22/T3/Line1). Jasmine reported on all but one feedback form that attending the psychoeducational support group reminded her at each session that things at home were actually going pretty well, shifting her perspective from needing to change her situation from feeling as if things needed to be improved. The group reminded her that her son was relatively well behaved. She attempted to switch her focus to that, rather than the difficulties he was having. She elaborated:

> When we're at home, we get bogged down with 'Okay, he's not doing this. I just called him ten times in the morning and he's laying on the bathroom floor'. But he really does have a quirky personality; he jokes around… he is quite a funny kid. He really tried to be funny, and it does make me appreciate him more, because we've even been joking around with him more, which never would have happened before. We just appreciate that he's a fun loving kid. He's really quite uplifting most of the time. (22/T9/Line1734)

Often Jasmine's reflections of her son's behaviour were provoked by the discussions of other participants' struggles at home. Many times, Jasmine commented that the shift in her perspectives of Logan's behaviour from negative to positive was spurred by the comparison of her son's behaviour to the experiences and struggles shared by other members of the group. When comparing her son's behaviour and the issues and struggles they had at home to those of what others shared in the group, her outlook would often shift from concern to that of gratitude. This was also reflected in Jasmine's rating scale after the intervention was completed, where she rated the group as *very helpful* for meeting other families with similar problems and hearing how other families were coping. As Jasmine outlines:

> It's horrible to say, but it helps us when they talk about the problems they have at home, because really [he] doesn't have behavioural problems and he's pretty compliant…we feel pretty lucky that [he] is the way he is. He could be way worse, so it gives us hope. (22/T9/Line1188)

At times, Jasmine appears to be relieved at this realization, and was thankful that Logan's behaviour was not as extreme:

> He basically tries to do what you want {laughs} eventually. It might take him awhile, but he's pretty compliant compared to some of them that are just 'I'm not doing it' and they walk out the door. What do you do then? So, thank heavens he's not like that. We're happy. (22/T2/Line900)

Overall, Jasmine's shifting perspective of her son's behaviour and personality to view the things she appreciated was a major benefit of the psychoeducational support group for Jasmine.

Attending the psychoeduational support group not only helped Jasmine to focus more on Logan's positive attributes, but it helped her to reevaluate her expectations of him, both positive and negatively. Before attending the support group, Jasmine had begun to believe that her son might never live independently; living on his own and having a job might be beyond his capabilities. However, after attending the group for a few months and learning about the supports in the community from the facilitators and other members of the group, she began to change her expectations and expand her future aspirations for her son. Jasmine indicated that the group helped her to "have more confidence in Logan's abilities" (22/T8/Question22). She continues:

> Honestly, when we first started going to the support group we thought that [he] may even have to go to a group home, because we thought there is no way he's going to be living on his own. But once they started talking about different support and help that he can have after he graduates, it's like 'Oh geez, he might not!' (22/T2/Line972)

In addition to changing Jasmine's perspectives of her son's possible future, participating in the group also aided in changing Jasmine's expectations of his daily living skills. Through Jasmine's experiences with the group, she was often reminded that a lot of Logan's behaviour was not intentional but instead of a function of her son's disability. "After the last group, I tried to see [him] differently, and not think he's is not 'wanting' to do something, and instead he 'can't' remember to do the activities. The group helps me to see the good in him" (22/T4/Line1). Jasmine knew this to be the case, but she often lost this outlook but during the day-to-day activities at home. The support group provided her the opportunity to be reflective of his behaviour and to reframe his negative behaviour as unintentional.

> Sometimes you'll be saying something to him and then you realize he's doing what he can and you give him the benefit of the doubt…Then, you might switch the way you're saying it to him. I think that's been extremely helpful. (22/T9/Line1234)

Despite being aware of her son's learning and memory difficulties, the group was a good reminder of our to change strategies and her approach.

Differentiating developmentally-appropriate behaviour. Along with changing her expectations, through discussions during support group sessions, Jasmine was continually attempting to differentiate between typical behaviour and behaviour that could better be attributed to Logan's difficulties with FASD. Her son with FASD was her oldest child and at times she found it difficult to determine what was typical developmental behaviour. At times, this was discussed during group sessions. "We've never had a teenager before him. He's the first one, so sometimes he's yelling at [his dad] – because of the FASD or is it because he's a teenager?" (22/T2/Line172). The support group helped to determine what might be above and beyond developmentally appropriate responses to situations through talking with other parents about their children, as well as hearing feedback from the facilitators: "Something pops up and [the facilitator] will go, 'You know, my 'normal' kids' do the same thing…'" (22/T9/Line1338). Additionally, the 'FASD 101' information session (basic information shared about FASD from the Edmonton Fetal Alcohol Network), also helped Jasmine and her family to determine what lens was most appropriate when thinking about his behaviour, which was also reflected on the rating scale, where she rated the group as *very helpful* for learning from others' experiences and receiving support when needed, such as having discussions about particular behaviours when needed.

Learning from others; "A sounding board". By talking with other caregivers, Jasmine was also able to recognize the universality of their experiences and create a feeling of connection through their shared experiences. Hearing the similarity of her experiences, both their struggles and triumphs, to that of others helped Jasmine to feel less alone: "There was a reassurance and that we're not alone. We're not just the only ones here dealing with these issues" (22/T9/Line2151). She enjoyed connecting and chatting with other parents, which again helped her to appreciate her own experience. "I like how afterwards generally people can mull around for a little bit. I'd say it's a good atmosphere for opening up to other caregivers"

(22/T2/Line1148).

In addition to reassurance, Jasmine indicated that it also provided helpful guidance to approach situations or struggles at home. Having similar experiences allowed Jasmine and other caregivers to share their approaches, strategies, and suggestions. Jasmine described it as a "sounding board" (22/T9/Line2182; 22/T8/Question16), a place where people could bounce ideas off one another and receive feedback or brainstorm how to approach or deal with situations. "It's very helpful that you can voice your opinions and we're going to listen…It's like a sounding board and can help you with your daily living, your daily issues, that come up" (22/T9/Line2182). The support group was beneficial for Jasmine because through sharing their experiences and recognizing the common group, she felt she could trust and support other participants of the group. As such, she rated the group as *very helpful* for sharing her feelings, challenges, and successes, as well as for meeting new people.

Access to resources. Through using the group as a sounding board, and hearing other caregivers' questions, Jasmine was also able to learn about additional strategies and resources she could use as well, which was reflected in her ratings of the group: learning about services, practical solutions, strategies, services for where to get help, and how to deal more effectively with Logan were rated as *very helpful*. Both the facilitators and the other caregivers shared information about resources in the community as well as examples of strategies they have used. A few strategies shared in the group during the study were particularly helpful for Jasmine. First, learning from other caregivers, Jasmine reflected that they had not been focusing enough on the positives enough at home. Instead, she and her husband often yelled or "nagged," rather than trying to reinforce positive behaviour.

> We were not positive with him at all. Honestly, probably the first four or five years we

> were like, 'You're doing that wrong. What are you doing? You're supposed to do this. Blah blah blah. We were never, 'Good job that you tried to do this'. … We just kind of used trial and error." (22/T2/Line689)

During one session, another caregiver focused on her own experiences with her daughter with Oppositional Defiant Disorder (ODD) and the success she has through ignoring her behaviour. After the session, Jasmine tried this approach and remarked how successful this approached had been for her. It helped her to deal with her daughter with ODD and reduced the amount of times she had to give a time out, which often meant screaming as a result. In addition, Jasmine's new approach also meant her son also did not get "worked up" (22/T7/Line1), which reduced the tension in the home.

Jasmine and her family learned about several resources in the community: possible summer camps for children with disabilities, services through Child, Adolescent, and Family Mental Health (CASA) and Dreamcatcher Association (a psychological practices that incorporates Nature-Assisted Therapy and Animal-Assisted Therapy), as well as funding through Family Support for Children with Disabilities (FSCD). These were all services Jasmine reported being unaware of prior to their involvement with Coaching Families. Jasmine indicated she wanted to learn more about services in the community, as she believed she was not be aware of all that is available, and hoped that the psychoeducational support group could help her to learn more. She specified, "Especially now that he's going to be going into high school – there must be other things".

Barriers. Conversely, several barriers or negative experiences or elements that appeared to be unhelpful for Jasmine as she attended the psychoeducational support group, although no element of the group was rated by Jasmine to be *not helpful*. Some barriers identified for Jasmine in interviews and feedback forms included: (a) Shyness and Need for Social Connection, (b) Negative Interactions within a Cohesive Group, and (c) Facilitations of Information Sessions.

Shyness and need for social connection. During psychoeducational support group sessions, Jasmine was relatively quiet compared to other participants in the group. She participated when asked questions directly, but only occasionally shared information beyond that. Jasmine's Coaching Families mentor was the facilitator for the psychoeducational support group, which helped Jasmine to first attend the group. She often attended the support group with her husband, who was also quite shy. Despite Jasmine's reserved nature, the support group helped Jasmine to feel connected and reassured that she was not alone. However, once she left the group and was in her regular routine, Jasmine reported she often again felt lonely (22/T9/Line2166). Even though she felt some connection with others in the group, she continued to feel somewhat lonely. These feelings were mirrored on the rating scale of the intervention components, where she indicated she the group was only *somewhat helpful* for "feeling less isolated and alone" (22/T8/Question12g).

Negative interactions within a cohesive group. Some of the interactions Jasmine had with other caregivers were less than positive. Jasmine enjoyed many of the regular participants at the support group, many of whom had the same Coaching Families mentor. Since many caregivers had attended several sessions together, the dynamics of the group had been established. Caregivers listened to one another and provided feedback when needed. The support group was relatively fluid, and additional caregivers beyond the core group often attended sessions, sometimes floating in and out of the group. For Jasmine, these additional participants, and the way they interacted with other caregivers, greatly reduced the helpfulness of the group for Jasmine. "He was a very forceful kind of guy… I felt kind of intimidated by him"

(22/T9/Line1968). Despite these negative interactions, Jasmine wanted to continue to have the support group as an open group for all caregivers of children with FASD.

Facilitations of information sessions. Overall, Jasmine indicated that the majority of information sessions were helpful for her, particularly for learning about programs in the community; however, some of the presenters for the information sessions Jasmine felt were less than captivating. One presenter was particularly disorganized and Jasmine felt she was wasting her time, "She didn't seem to have anything prepared. Why are we listening to this?" (22/T9/Line1900). As Jasmine reported on the Rating of Intervention Components completed post-intervention, "Some presenters were kind of dull" (22/T8/Question18). Despite this feedback, Jasmine indicated that overall the information sessions were helpful (i.e., rated *very helpful* on the rating scale), specifically information sessions on FASD and youth justice issues, Alberta Caregivers Association, and holiday luncheons with social workers from the Coaching Families program. A suggestion from Jasmine regarding possible future information sessions included a psychologist who would be available for caregivers to ask questions regarding their children's development and behaviour.

Case two. Several aspects of the psychoeducational support group were identified by Terry to be both benefits (i.e., elements that were helpful) and barriers (i.e., elements that hindered her ability to have a positive experience) for attending the group.

Benefits. A few benefits of the psychoeducational support group for Terry were identified, including: (a) Making Social Connections: "All in the Same Boat," (b) Envisioning a Positive Future, and (c) Learning About Resources for Now and the Future.

Making social connections: "All in the same boat". One of the key benefits of participating in the psychoeducational support group for Terry was Terry benefited from making connections with other caregivers we attended the group through sharing experiences. This was also reflected in Terry's ratings of the group, as elements related to social connection were rated as *very helpful* for her: meeting new people, feeling less isolated, feeling understood, sharing feelings, and getting support from others. The nonjudgmental attitude of the group helped Terry to open up about her own difficulties:

> It's a great outlet. It's just so great to go and hear other people talk about other things, to get ideas, and to be with like-minded people that aren't going to judge, because you're all in the same boat. You all get it, you know, and you don't have to worry about people with these preconceived notions about FASD. It's just a good place. (23/T9/Line2461)

There were two caregivers in particular that Terry connected with, as indicated by observations and interview information. One caregiver was in the process of adopting a son with FASD and came to the group only once (23/T5/Obs). The other caregiver was a regular participant at the psychoeducational support group. After attending the group for a few months, during one session in particular, Terry had become very quiet. Following the session, the other caregiver approached Terry and asked her how she was doing, and provided insights to Terry about ways to cope when the "honeymoon period" was over (23/T7/Line36). Terry recounted in the post-intervention interview that they talked for a while after the session was over, both inside and then outside the facility, and that they exchanged information in order to chat further in the future. Terry described that it was helpful to debrief with someone about how she had been doing since her son's behaviour had escalated and she had advocated for additional support. This was particularly helpful because by that time Terry had not yet told anyone in her family that her son was suspected of having FASD, and therefore, she had not had the opportunity to talk with anyone outside of the psychoeducational support group about this experience.

Envisioning a positive future. Another key benefit for Terry was how it helped her to envision her families' future. Terry had only adopted her son a month prior when she began attending the group. This suggested that everything was new and unknown for Terry at that stage of the adoption process. It was helpful to have a source of information of how their future may look, or at least make the future less unknowable:

> It provided insight into our future. One of the parents with several children gave some great suggestions. It was nice to see the future not as a big unknown but as something manageable, like the other parents who adopted a child who is now a teenager. (23/T3/Line1)

Particular parents provided information for Terry that was helpful. Specifically, there were two caregivers that attended the group that had adopted their children at 6 to 8 years old and now their children were teenagers. The experiences of these caregivers were particularly helpful for Terry because she was able to hear about their successes that gave her hope, which was reflected in Terry's ratings of the group (i.e., meeting others with similar problems, learning about others' experiences, and sharing challenges and successes were all rated to be *very helpful*). These caregivers helped to provide Terry with the perspective that she sometimes needed to help her look to their possible future together, and to look at the bigger picture overall. "I just love hearing about those stories, particularly the ones that have adopted, of course, and they've grown up with them, because that just gives me kind of so much hope" (23/T9/Line2300). Terry elaborated how learning about one particular caregiver's experiences were helpful: "She's done it. She just has so much experience, and so many ideas…Just knowing that I could call her anytime and ask for suggestions, or just for a chat" (23/T9/Line2168).

Learning about resources for now and the future. Not only was Terry able to learn from others' experiences about their successes and difficulties, but other caregivers also provided resources for Terry. Learning about how others were dealing with their problems, strategies, services, practical solutions, and where to get help were all rated to be *very helpful*. Caregivers provided information about what resources they have accessed and have found to be helpful. "There is lots of information and resources that get shared. It's just impossible to know everything, right? And so as time goes on, you just learn more and more about what's available out there" (23/T9/Line2473). Terry often made notes of resources, both that she could access now, but also lists of resources that could be accessed in the future if needed. Some resources were general, but others were more specific about programs. For instance, even resources like learning what camps have been successful for children with FASD were helpful to learn for Terry for the future. Learning about these resources helped to decrease Terry's own fear about the future:

> I guess there are so many things that could go wrong in the future. It's a big unknown… It's really nice to know that there are resources out there that can help us. Just knowing about some of them, and knowing where to access the, it just kind of helps. It relieves some of that anxiety in my brain, because I don't really have to worry about it. I can focus more on the now. (23/T9/Line2194)

One example included Terry learning about other caregivers' successes and challenges with the school system. Even though Terry did not have to think about these particular decisions in the present, she appeared to retain this information so it could be used sometime in the future when needed:

> One couple adopted their son at six and now he's a teenager. Just learning some of that stuff that they're going through right now, especially as he's going into high school.

> That's going to help me so much looking at the future. I'm so focused right now, but I do have those little worries about the future. So those little bits that I learn there are going to help me when it's time to pick a junior high and a high school. (23/T2/Line1122)

In addition to specific community resources, specific strategies that other caregivers had found successful were also beneficial to Terry. For example, during one session, caregivers spoke about their experiences of discussing with their children about FASD and what that means. As Terry remarks, "I probably read it somewhere, but it was nice to hear that real life experience of actually doing it" (23/T9/2284). Hearing these experiences, as well as learning about community resources, reiterated to Terry that she was not alone, and that if she did need additional support she now knew where it could be accessed.

Barriers. In addition to the three benefits outlined previously, two barriers were also identified for Terry as she attended the group: (a) "Group Facilitation," and (b) "Timing of the Group."

Group facilitation. One aspect of the group that Terry suggests could be improved is how the group begins. Terry indicated that often times it appears as if it takes the group some time to get started and to allow people the chance to open up. Sometimes it is not until the open discussion portion of the psychoeducational support group is almost complete that people seem to be relaxed and feel comfortable enough to talk honestly about their struggles and successes. One suggestion that Terry has made it changing the structure of the group so the support group begins with one particular topic, rather than being open ended, which may better facilitate the discussion and "spearhead some more of the conversation" (23/T9/Line2385). In addition, Terry indicated on the rating form that facilitation by one guest speaker was *not helpful*, as she did not find it particularly engaging.

Timing of the group. Another barrier for Terry attending the group were conflicts with her work schedule, which was also a difficulty for other participates. This was particularly problematic when the time and day of the psychoeducational support group was shifted. For example, one of the monthly sessions was rescheduled from a Wednesday morning, when it was typically held, to a Thursday morning. For Terry, that meant that she needed to change her work schedule, which was not possible. Therefore, unfortunately Terry had to miss the group meeting that month. She attended all other sessions conducting during the study. At the time of the study, Terry was taking some time off work while her son settled into his new home. She was concerned that when she went back to work she would no longer be able to attend the psychoeducational support group. Terry was going to attempt to continue to attend the group, but she was concerned that she would not be able to fit it in due to all the other days she would be required to take off because of professional development days or sick days. Despite these difficulties, overall Terry believed the timing of the group was favorable because it seemed to work for the majority of families attending.

Case three. Several aspects of the psychoeducational support group were identified by Janelle to be both benefits and barriers for attending the group. Benefits were conceptualized as elements of the group that the participant felt to be helpful; whereas barriers were unhelpful aspects that at times hindered her ability to have a positive experience of the group. Janelle had been attending the psychoeducational support group for approximately six months at the beginning of the study

Benefits. A few benefits of attending the group were identified for Janelle: (a) Building Each Other Up, and (b) Changing Expectations. Janelle's benefit of Building Each Other Up was further divided into two categories: "'A Humbling Feeling of Understanding'" and Providing

Advice: "Giving My Two Cents."

Building each other up. The most beneficial aspect of attending the psychoeducational support group for Janelle was two fold: her own process of hearing stories from other caregivers and feeling that she was not alone in her experience as well as the joy *and* the competence she felt when she was able to provide strategies that was grounded in her own practical knowledge that she thought may also be helpful to someone else. Both of these elements were congruent with ratings post-intervention. Jasmine rated meeting others with similar problems, feeling less isolated, feeling understood, getting support and feeling support were rated as *very helpful*, as was sharing feelings.

"A humbling feeling of understanding". Janelle found it hard to first attend the group. When she first learned about the program, Janelle was not interested in participating. At the time, she felt everything was under control. However, when the situation began to appear more long term, and issues with her daughter began to arise, She was in the midst of the going to court for custody of Sarah, and she was under a lot of pressure at the time. She felt she did not want to share her difficult problems with a room full of strangers. Janelle realized she could use the additional support: "I thought, I could probably take some advice from somebody" (25/T2/Line779). It took a lot for her to attend her first session and when she did she felt "overwhelmed." As Janelle describes:

> When I first came, I would cry… It's like that feeling of overwhelmingness. You can't even describe it. You're just, 'These are the problems, there are so many problems.' But once you start talking about them, things start moving and it's not so bad anymore. These are the problems, *but* there's all these good things too." (25/T2/Line1589)

Janelle immediately understood why attending the group was helpful for her. Although Janelle also learned strategies from other caregivers, that was not the most beneficial aspect for her. Instead Janelle appreciated feeling connected with other caregivers, as it gave her hope and provided a new perspective on what was going on at home. She described attending the support group as "calming" (25/T2/Line902) because she can relate to what others are experiencing and it makes her feel less isolated and that her child's behaviour is not unique. For example, when her daughter is having a tantrum in a store, "It's like the worst feeling, but then you hear six other people say that they're kid does it too, and then it doesn't seem so bad" (25/T2/Line1303). It was an alternative, non-judgmental place that allowed space to talk freely about what she was experiencing, something she had not experienced before:

> It's not like I have a whole bunch of friends who have kids, so it's nice to go somewhere where you can say something and people aren't like, 'Oh yea, you got a problem' … You say something and everyone is like, 'Yea, that sounds about right.' You can't get that anywhere… It's a humbling feeling of understanding. (25/T9/Line972)

In addition to hearing others' perspectives and stories, Janelle made a strong connection with one other participant in the group and they became friends. They often sat and laughed together, and would often chat during breaks. They sometimes see each other outside of the group and often talk on the phone. Janelle described that they have the same sense of humor and a lot of other things in common, including daughters that were similar in age.

Providing advice: "Giving my two cents". Janelle enjoyed hearing others experiences and also strategies from other caregivers. Although she did not always take advice from others, in general she appreciated hearing other's perspectives; "I'm really open to learn and listen" (25/T2/Line1327). Hearing others' strategies helped Janelle in stressful situations, both reminding her that other caregivers also deal with similar stressful situations and providing insights into things she could possibly try.

> When you're in the middle of Superstore and your kid is losing their mind, it's the worst feeling, but then you hear six other people say that their kid does it too, and then it doesn't seem so bad. And then the next time that happens, I have five ideas that I can pull out that I wouldn't have had before. (25/T9/Line992)

Sharing her own perspective and ideas of how to approach situations also made Janelle feel competent and successful as a parent. Janelle felt her parenting skills were an area of strength for her, and providing information to others made her feel proud. It reminded her how far she had come and what she had learned during her time taking care of Sarah. "I like listening to other people, what they have to say, and giving my two cents somewhere" (25/T2/Line1492).

Changing expectations. Even though Janelle had a strong interest in parenting and was relatively knowledgeable of FASD, she also indicated she had to change her expectations of Sarah. In particular, she struggled with the idea that FASD "wasn't changeable" (25/T2/Line1345). Even though she knew this was the case, she had difficulties accepting it. "Initially, learning this is not something that's reversible, no matter how well you parent your child. This is not going away. I think this has kind of humbled me in a sense. Now I look at it with that perspective" (25/T2/Line1350). This process occurred both inside and outside of the group, and influenced how she interpreted the suggestions of other caregivers. "It's not fair to preach at people. You can't say that every kid is going to get it… It's unfair" (25/T9/Line649). This was reflected in her ratings of the group (i.e., learning about others' experiences and how others were dealing with their problems were both rated to be *very helpful*). This knowledge and understand also influences what strategies she shares with other caregivers.

At the conclusion of the study, Sarah had been in Jasmine's care for approximately three years. Janelle's adoption of Sarah had been somewhat of a surprise. Sarah's biological mother had created a safety plan with Janelle for Alberta Human Services that included Janelle taking care of Sarah if needed. However, Janelle thought there was only a small chance that the safety plan would be used, and if so, she believed it would only be for a few days. Shortly after Sarah was diagnosed with FASD, Sarah's biological mother asked Janelle to take care of Sarah. Since that time, Janelle has been given a Permanent Guardianship Order and she was in the process of adopting Sarah at the time of the study. Janelle reported that Sarah's behaviour has improved drastically over the last three years, although she continued to have difficulties with attention and concentration, and at times she would through temper tantrums, which Janelle found very embarrassing if they were in public when they occurred. Learning what was reasonable to expect from her daughter helped her to learn how best to manage her behaviour.

Barriers. In addition to the three benefits outlined previously, three barriers were also identified for Janelle as she attended the group: (a) Difficult Interactions: Wanting a Small Group," and (b) Disconnection with Some Information Sessions. Janelle also had difficulties with attending due to conflicts with her work schedule. As a result, Janelle was unable to attend one session conducted during the study.

Difficult interactions: Wanting a small group. Similar to Jasmine's experience, at times Janelle's interactions with other caregivers at the psychoeducational support group were less than positive. At times, Janelle became resentful when other caregivers attempted to provide her with advice or strategies when she did not believe they understood her experience, or understood the nature of FASD and how every child is different. Instead, she felt they were lecturing her rather than being constructive or supportive. "It kind of bothers me when people come into the support group…and they almost start preaching. Like 'this is the way you should do it'… It's not fair to preach to people." (25/T9/Line660). Janelle's advice from this experience was to have the boundaries of the group clarified before the group began in order to avoid situations where someone feels singled out, or to have facilitators redirect the conversation to be more constructive and less punitive.

At the beginning of the study, Janelle was enthusiastic to have additional caregivers join the group. She believed that the support group could be improved by recruiting other caregivers to participate in order to make it larger. However, by the end of the study, having these negative interactions with other caregivers, she had reversed her initial thoughts. By the end of the study, Janelle indicated, "I think I get a lot more out of support group when there is a solid group of people there, that have always been there, and we all kind of know each other's kids in a sense" (25/T9/Line738). Having a dedicated group of participants that attended the group every month allowed caregivers to develop relationships and build trust, which in term allowed Janelle to feel more comfortable to talk about her own experiences as well as learn from other members in the group.

Information sessions. Janelle also had a similar experience to Jasmine in that a few of the information sessions were somewhat disconnected to her needs as a caregiver, which was reflected in the one element of the group she rated as not helpful. In particular, two information sessions were unhelpful for Janelle. One information session, which occurred prior to the study, was a presentation by a organization that provides respite care. Janelle felt the information session was inappropriate because the majority of children could not attend the home, either because of financial constraints or because of restrictions due to significant behavioural challenges. The second information session was a presentation that focused on self-care for caregivers. Instead of helping Janelle, both information sessions made Janelle angry and resentful for the time that was wasted:

> I come there to get something out of it. So I'm sitting there and I can't believe I'm listening to you talk for two hours about nothing, and I could be working! I mean, I would much rather listen to people talk about real life things and throw out ideas." (25/T9/Line866)

This connection was also reflected in Janelle's ratings of the group (i.e., these two sessions were rated to be *not helpful*). For Janelle, this reiterated that the most beneficial aspect of the group was listening to other caregivers' stories and brainstorming strategies. Overall, feedback from Janelle suggested she would prefer to only attend the support group portion of the group, instead of the information session as well.

Summary of Individual Caregiver Themes

Several commonalities among caregivers' experiences of benefits and barriers arose from deductive coding of individual experiences, as well as from related a priori categories through inductive coding. Despite these commonalities, through inductive and deductive doing several themes emerged for each case that were unique and best described each caregivers' experiences overall. These themes were based both on quantitative and qualitative data gathered throughout the course of the current study. The themes for each case are described below.

Case one. In addition to benefits that are typically associated with participant involvement with support groups, the analysis of Jasmine's case posited three overall themes unique to her experience of benefits and barriers, and associated a priori factors: (a) Reassurance: Translating Parental Knowledge Into Self-Efficacy; (b) Time for Reflection; and (c) A Need for Additional Support and Services.

Jasmine's involvement with the psychoeducational support group impacted her knowledge of effective parenting strategies and issues related to FASD. Overall, Jasmine described herself as relatively knowledgeable as a parent; however, this knowledge did not appear to translate into increased confidence for her. Her lack of confidence appeared to not be specific to her parenting skills, but was in line with how she felt in many areas of her life. Jasmine indicated she thought parenting would come naturally to her, as she felt it had been for her mother. Because Jasmine did not feel confident as a parent, the psychoeducational support group was helpful as a source of reassurance for her. It helped her to translate her knowledge into feelings of self-efficacy. It provided resources and strategies for her to feel effective as a parent.

One way that helped Jasmine feel less stress as a parent was to have opportunities to reflect. This was true both in her involvement in services, including the psychoeducational support group, and the ways she coped with stress at home, such as connecting with her husband at the end of the day or having a few minutes alone. The group also provided a venue for reflection. By hearing stories from other caregivers, Jasmine had the opportunity to hear what other caregivers were dealing with at home, which often aided a change in perspective or reiterated Logan's strengths. It also broadened Jasmine's hopes for Logan's future.

Despite feeling connected with other caregivers, Jasmine reported that once she left the group she often once again felt isolated and alone. Jasmine indicated that the group helped her to feel less alone, and reminded her of the universality of her experience, but this feeling did not always last been monthly sessions. For Jasmine, this reiterated the need for additional relationships with other caregivers outside the group to foster feelings of connection and a social system, as well as additional services, such as the Coaching Families program. Jasmine was relatively shy as a parent, and therefore, these connections took time to foster. Therefore, additional services were beneficial for Jasmine, including the Coaching Families program as the benefits of the group could not be sustained for Jasmine from session to session.

Case two. The analysis of Terry's case posited two overall themes, related to the typical benefits associated with support groups, but unique to Terry's particular case: (a) The "Newness of It"; and (b) Gaining Advice and Information as a New Advocate.

Terry was in a unique position attending the psychoeducational support group and the current study. As a new adoptive parent, she had a unique perspective. As she divulged, this added a complex layer to the stress that she was experiencing. Her family was in the process of navigating their new roles. The psychoeducational support group provided an avenue to hear from other caregivers who had already been in this position of recently adopting a child and could provide some guidance, as well as reiterate the universality of their experience. As Terry stated, hearing from other caregivers helped her to look to the future with less stress and uneasiness, and instead it helped her to envision a positive future for her son.

Not only did Terry benefit from hearing other caregivers' stories in order to envision a positive future, Terry soaked up information that she felt she could use either in the present or in the future. As Tyson's behaviour escalated and his outbursts continued, Terry continued to gather information and services that she could access if needed. Terry had already advocated on many occasions for her son during the first few months that he was in her care, and she was always prepared to do so again if necessary. In the short time that Terry has cared for her son, she has already proved to be an advocate for her son. The first month or so, Terry described as a "honeymoon" period, and after having her son lived with them for a month he began doing some "testing" (23/T2/Line33). His behaviour began to escalate, and his aggressive behaviour increased, including scratching. He was also often swearing and at one point engaging in very unsafe behaviour that included climbing on the outside of their second floor interior railing.

Terry took a video of the incident and sent it to her son's adoption worker as a cry for additional services: "Ok he's putting himself in danger now. He needs something…We just felt he needed more. He needed somebody to talk to that wasn't mom and dad. So they got him a youth worker" (23/T2/Line15). When asked about her advocacy skills and what was needed to obtain extra services, Terry replied, "I just pushed…Maybe it's all the training that I took led me to what to expect" (23/T2/646).

The information she gathered during the group helped her in this new advocate role. She also learned new strategies and approaches, but it appeared that learning about resources and supports in the community was most beneficial for her. In addition to learning from others' experiences, she also often solicited advice regarding what services were most appropriate. Terry continually gathered information in order to best support her son, both now and in the future, and attending the group helped in this role.

Case three. Analysis of Janelle's case posited two overall themes for Case Three: (a) Providing Social Support: A Safe Space Without Judgment; and (b) Cultivating Parental Efficacy. Both of these aspects, building social support and extending her parental efficacy, were important for Janelle, as she did not have the additional support of a spouse at home.

Janelle's involvement with the psychoeducational support group provided additional social support, which was very important for Janelle. This was highlighted both by how she handles stress and what she found most helpful from the group. When asked what she typically does when she is particularly stress, Janelle indicated she would immediately call friends and family to talk through the situation or to ask for respite services. Additionally, her feedback during the study indicated she enjoyed having the opportunity to talk with other parents, which was so important for Janelle that she preferred to extend the support group portion of the group rather than attend the information sessions. Furthermore, one area of stress for Janelle was being in public while Sarah was having a meltdown and feeling as if others were judging her. The psychoeducational support group provided a space for Janelle that allowed her to talk openly and honestly about her experiences with other caregivers that understood what she was going through.

Janelle's involvement with the psychoeducational support group also provided opportunities for Janelle to share her own successes and provide advice and guidance to others. This appeared to be an important theme for Janelle as it increased her confidence. Janelle had always had a particular interest in parenting philosophies and strategies, and since she was young she wanted to adopt children. The psychoeducational support group helped Janelle to share about her own concerns; but she also shared her successes and provided insights into what other may be experiences, which helped her to grow her own sense of parental competence. This process helped to strengthen her own internal resources when faced with difficult stressors in her daily life.

Research Question C: Cross-case Comparison

This section focuses on the cross-case analysis for a multiple case study. Individual case studies explored caregivers' benefits and barriers of participating in the psychoeducational support group. First, focus is placed on a comparison of the a priori categories (i.e., stress, sense of competence, support, and quality of life) across cases. Second, the discussion will be extended to explore a comparison of the benefits and barriers to participating in the group across cases. Specifically, this section addresses the third subresearch question: what are the similarities and differences of caregivers' experiences of participating in the psychoeducational support group when compared across individual case studies? Both qualitative and quantitative data were collected to address this question. Cross-case analyses was used to compare data derived for Research Questions A and B in order to identify similarities and differences across cases.

A priori factors. Caregivers' experiences of several prefigured or a priori categories were investigated including stress, parenting sense of competence, social support, and quality of life. Caregivers' experience of these factors related to their participation with the psychoeducational support group was the primary focus, although their broader experiences of these factors in daily lives were also addressed in order to provide a rich description for individual case studies.

All caregivers were experiencing significant amounts of stress throughout the course of the psychoeducational support group and completion of the study. Table 4 provides an overview of information that was gathered regarding experiences of stress for each individual case study. This was reiterated by information gathered on the PSI/SF, interview information, and qualitative information on feedback forms. All of the caregivers' total scores on the PSI/SF fell in the High Score (at or above the 85th percentile) or Clinically Significant (at or above the 90th percentile) ranges. Interestingly, caregiver stress levels were least elevated (at or below the 85th percentile) for the factor of Parental Distress on the PSI/SF, which measures the distress a caregiver is experiencing in her role as a parent and the factors that are directly related to that role (e.g., parental competence, social support; Abiden, 1995). In comparison, the Parent-Child Dysfunctional Interaction and the Difficult Child factors were significantly elevated for all three cases. These factors measured the caregivers' perception of that her child does not meet the caregivers' expectations and that the interactions may not be reinforcing to them as a parent, as well as the basic behavioural characteristics that make a child easy or difficult to manage, respectively (Abiden, 1995). As such, the caregivers' perception of their stress could be

Table 4

Summary matrix of participants' experiences of the a priori factor, stress.

	Case One: Jasmine	**Case Two: Terry**	**Case Three: Janelle**	**Comparison**
		Stress		
Parenting Stress Index/Short Form (PSI-SF) Total Scores[4]				
Pre-intervention	99th percentile	97th percentile	87th percentile	*Similarities*: all ratings in "High Score" or "Clinically Significant" ranges
Post-intervention	95th percentile	99th percentile	94th percentile	
Coaching Families FASD Stress (CFS) Scale Total Scores				
Pre-intervention	22 (out of 64)	23 (out of 64)	25 (out of 64)	*Relatively similar* with the exception of Jasmine's post-intervention rating
Post-intervention	15 (out of 64)	24 (out of 64)	28 (out of 64)	
Mean rating	*Rarely*	B/t *rarely* & *sometimes*	B/t *rarely* & *sometimes*	
Sources	• Chaos at home • Logan's lack of friends • Respite services • School system • Guardianship • Behaviour	• Lack of sleep • Extreme behaviour • Newness of the experience • Unhelpful people • Transitioning back to work	• Judgmental attitudes • School system • Side effects from medication • Extreme behaviours • Appointments and maintaining employment	*Similarities:* • Behaviour (all caregivers) • School system (2 out of 3 caregivers) *Differences* due to individual experiences

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[4] A percentile score refers to the caregivers' placement relative to other caregivers' responses on the norm-referenced test. The higher the percentile, the higher the stress levels. For example, a score at the 60th percentile indicates that, when compared to other caregivers, the caregivers' level of stress is ranked the same as or higher than 60% of them. A score at or above the 85th percentile is a High Score. A score at or above the 90th percentile is Clinically Significant. Out of 100 caregivers, the middle 50 are considered to be average so, average scores would fall between the 25th and 75th percentiles.

Table 4 continued.

Reported increase or decrease of stress	Decreased due to increase of mature behaviour	Increased due to escalated behaviour	Increased due to financial stressors and difficulties at school	*Differences:* both increases and decreases over time
Group aspect that largely helped with stress	"Time for reflection"	"Hearing positive outcomes and learning resources"	"Social support"	*Differences* based on individual experiences
Rating scale: Feeling less stressed as a parent	*Very helpful*	B/t *somewhat helpful* & *very helpful*	B/t *somewhat helpful* & *very helpful*	*Similarities:* either somewhat helpful or very helpful ratings
Summary	↓	↑	↑	*Differences:* Both ↓ and ↑ overall

conceptualized as being directly related to raising a child that is difficult to manage, rather than lacking the skills, training, resources, and support needed to match the needs of their children. The stress was perceived outside the personal factors related to their role as caregivers, and instead, was a result of their child's difficult behaviour and parent-child interactions, due to the primary disabilities and adverse outcomes typically associated with children with FASD, including behavioural, social, and emotional difficulties. Caregivers decreased stress levels related to Parental Distress may have been a function of their involvement with programs and services aimed at reducing stress levels, such as the Coaching Families and psychoeducational support group programs, or it may be a broader experience of caregivers of children with FASD.

The stress levels of two caregivers, Terry and Janelle, increased over the course of the study, whereas Jasmine's stress levels decreased over this time. All three caregivers reported that the group was somewhat helpful or very helpful for dealing with feelings of stress. Changes in stress levels for the current study were not necessarily a function of participating in the group. Jasmine's stress decreased during the this time as a result of several factors: Logan's behaviour improved and appeared to become more mature, he was accepted into a specialized high school program, and the family increased their involvement with respite services. Terry and Janelle's stress also increased as a result of several factors. For instance, Terry's son's behaviour began to escalate after she reported the "honeymoon period" was over. Janelle began to be financially strained due to losing her job and needing car repairs. Additionally, Janelle's daughter was also having difficulties at school and a medication for her daughter was trialed that resulted in several side effects, including difficulties sleeping. Despite these difficulties, all caregivers regularly attended psychoeducational support group meetings and benefited in various ways previously described. In summary, the group provided Jasmine the opportunity for a time to reflect, including receiving feedback from others. For Terry, the group provided an opportunity to receive information and resources that helped reduce her fear of the future. For Janelle, the group provided a needed social connection in a nonjudgmental environment that reminded her of the universality of her experience.

All caregivers reported the psychoeducational support group was somewhat or very helpful for feeling more confident as a parent. Table 5 provides an overview of information that was gathered regarding parenting sense of competence for each individual case study. Nevertheless, the relationship of caregivers' parenting sense of competence to their participation in the psychoeducational support group was different for each case. Jasmine felt the psychoeducational support group, along with her participation in the Coaching Families program, helped to increase her knowledge of FASD and related issues. However, Jasmine reported this knowledge did not translate into feelings of efficacy. This may be reflected in her

Table 5

Summary matrix of participants' experiences of the a priori factor, parenting sense of competence.

	Case One: Jasmine	**Case Two: Terry**	**Case Three: Janelle**	**Comparison**
Parenting Sense of Competence				
Parenting Sense of Competence (PSOC) Scale Total Scores				
Pre-intervention	58 (out of 102)	59 (out of 102)	37 (out of 102)	*Differences* due to individual variation
Post-intervention	58 (out of 102)	64 (out of 102)	40 (out of 102)	
Mean rating	B/t *disagree* & *agree*	B/t *disagree* & *agree*	*Somewhat disagree* (indicating higher parenting sense of competence)	
Rating scale: Feeling more confident as a parent	*Somewhat helpful*	*Very helpful*	*Somewhat helpful*	*Similar* ratings of somewhat helpful to very helpful
Related themes	• Positive reinforcement • Patience • Parental knowledge • Reassurance • Strategies	• Acceptance of diagnosis • Willingness to learn • Taking the time to learn and adapt • Dedication to whatever time is needed to help	• Understanding • Willingness to learn • Patience • Parental knowledge and strategies • Advocacy skills	*Differences* due to individual experiences
Summary				
Efficacy	↓	↑	↑	*Different* experiences
Satisfaction	↑	↓	↑	

total score and efficacy subscale scores on the PSOC both before and after the intervention. Although this scale is not normed, comparisons to previous research suggest her satisfaction and efficacy may be somewhat low. Despite feeling knowledgeable and satisfied with her role as a caregiver, she did not feel confident, which she indicated was related to overall feelings of insecurity overall. As a result, the group often provided reassurance for her that she was on the right track, as well as an avenue to receive information. Overall, Terry's responses on the PSOC were similar to Jasmine, but in interviews she reported she felt fairly confident in her new role. At times, she would sometimes question whether she was doing the correct thing and would spend a large amount of time changing behaviour programs and token systems, but overall she felt confident. The psychoeducational support group, along with behaviour consultants and the Coaching Families program, provided avenues to discuss these ideas, relay challenges, and hear success stores. Her low ratings of satisfaction were likely a function of the newness of her experience as she settled into the new role while also dealing with extreme behaviour. Finally, Janelle felt relatively effective as a caregiver, and satisfied. Rather than increasing her feelings of competence, the intervention largely provided an avenue to discuss stressors and connect with others.

All caregivers indicated they felt very supported by the psychoeducational support group and its members. Table 6 provides an overview of information that was gathered regarding experiences of social support for each individual case study. Caregivers could identify several areas of social support in their lives, such as spouse, kinship, information, and formal support, which included the psychoeducational support group. All caregivers could indicate areas in their lives, where additional support was desired, including through kinship relationship (i.e., Jasmine) and spousal support (i.e., Terry and Janelle).

Table 6

Summary matrix of participants' experiences of the a priori factor, social support.

	Case One: Jasmine	**Case Two: Terry**	**Case Three: Janelle**	**Comparison**
		Social Support		
Family Support Scale (FSS) Total Score				
Pre-intervention	20 (out of 95)	33 (out of 95)	20 (out of 95)	*Relatively similar* with the exception of Terry's post-intervention ratings
Post-intervention	29 (out of 95)	45 (out of 95)	29 (out of 95)	
Mean rating	B/t *sometimes helpful* & *generally helpful*	*Sometimes helpful*	B/t *not at all helpful* & *sometimes helpful* (lack of spousal support)	
Rating scale: How supported did you feel	*Very supported*	*Very supported*	*Very supported*	All rated "very supported"
Sources	• Kinship • Spouse/partner • Informal • Programs/ organizations • Professional	• Spouse/partner • Programs/ organizations • Professional support	• Kinship • Informal • Programs/ organizations • Professional	*Similar* sources of support with slight differences in emphasis (e.g., kinship versus informal support)
Summary	↓	↑	↑	*Differences* across cases

However, the social support reported by all three caregivers increased throughout the completion of the project, both on FSS ratings and through qualitative data. Social support was indicated to be one of the constant benefits of the group across all individual cases. Despite this support, Jasmine continued to struggle with feelings of isolation and loneliness at home. Terry and Janelle had both found bonds with other caregivers in the group, whereas Jasmine often attended with

Table 7

Summary matrix of participants' experiences of the a priori factor, quality of life.

	Case One: Jasmine	**Case Two: Terry**	**Case Three: Janelle**	**Comparison**
		Quality of Life		
Family Quality of Life (FQOL) Scale Total Score				
Pre-intervention	96 (out of 125)	86 (out of 125)	103 (out of 125)	*Relatively similar* ratings but *differences* based on individual experiences
Post-intervention	100 (out of 125)	92 (out of 125)	108 (out of 125)	
Mean rating	*Satisfied*	B/t *neither satisfied or dissatisfied* & *satisfied*	*Satisfied*	
Summary	↑	↑	↑	*Similarities* across cases

her husband and was more shy, quiet, and reserved. This reiterates the need for substantial social support outside the psychoeducational support group and family unit.

Although no causal inferences can be drawn, all FQOL ratings increased over the course of the psychoeducational support group and completion of the study. All caregivers indicated they were satisfied with their family life overall, although at times they struggled with specific aspects (e.g., difficulties traveling, engaging in public activities). It is hoped that by increasing social support and helping to deal with levels of stress, the psychoeducational support group helped caregivers to feel more satisfied and content with the daily lives. Table 7 provides an overview of information that was gathered regarding experiences of family quality of life for each individual case study.

Benefits and barriers. In review, each case highlighted several benefits for participating in the group. Table 8 provides a summary matrix table of the benefits and barriers for each caregiver, as well as common and divergent similarities and differences as a result of the

Table 8

Summary of case themes and comparison of caregivers' experiences of the psychoeducational support group.

	Case One: Jasmine	**Case Two: Terry**	**Case Three: Janelle**	**Comparison**
Benefits	• Shifting perspectives • Changing expectations • Differentiating developmentally-appropriate behaviours • Learning from others: “A sounding board” Access to resources	• Making social connections: “All in the same boat” • Envisioning a positive future • Learning about resources for now and the future	• Building each other up ○ ”A humbling feeling of understanding ○ Providing advice: “Giving my two cents” • Changing expectations	*Similarities* • Instillation of hope • Changing perspectives • Learning information about the disability and resources in the community • Social connection and feelings of belonging • Opportunities to hear and share experiences *Differences* • Providing advice • Differentiation of behaviours • Usefulness of the group based on child's age • Logistical elements
Barriers	• Shyness and need for social connection • Negative interactions within a	• Group facilitation • Timing of the group	• Difficult interactions: Wanting a small group Disconnection with some	*Similarities* • Difficult interactions with others • Childcare and timing • Information sessions not specific to FASD

cohesive group • Facilitations of information sessions	information sessions	*Differences* • Difficulties with facilitation • Continued feelings of isolation and lack of social connection

deductive analysis and cross-case comparison experiences discussed below (Miles & Huberman, 1994). Jasmine's case highlighted the positive benefits for changing her perspective about her son's behaviour and focusing on his positive qualities and characteristics instead. Terry's case highlighted the benefits for a new adoptive mothers, in particularly learning about resources and information related to FASD that she could use now and in the future. Jasmine's case highlighted the positive impact of social inclusion and connection for addressing her social anxiety related to taking her daughter into public places due to her frequent temper tantrums and negative behaviour. All of the caregivers found the psychoeducational support group was a place to hear and share stores and perspectives in a nonjudgmental space, while also learning information about FASD. When comparing the benefits and barriers across individual case studies, several similarities and differences arose. Specifically five commonalities across benefits were highlighted: (a) the Instillation of Hope; (b) Changing Perspectives; (c) Learning Information; (d) Social Connections and Feelings of Belonging; and (e) Opportunities to Hear and Share Experiences. Table 9 includes illustrative examples of common similarities and differences. Jasmine, Terry, and Janelle all indicated the group helped to instill feelings of hope, although in different ways and through different mechanisms. For Jasmine, the group helped her to change her expectations of her son and realize his abilities, which helped her to develop hope regarding her son's future. Through discussions with other caregivers and the facilitators, Jasmine often reframed her son's behaviour to focus on the positive aspects. This was also true for Terry. Terry also became more hopeful regarding her son's future due to the positive stories shared by other adoptive parents. Janelle's experiences within the group were also transformative; she often felt overwhelmed prior to the group but the group helped her to see a

Table 9

Clustered summary table of results of cross-case comparison with illustrations.

Caregiver Experience	Theme	Illustrative Examples
Benefits		
Similarities	Instillation of Hope	Terry: "I just love hearing about those stories, particularly the ones that have adopted, of course, and they've grown up with them, because that just gives me kind of so much hope." (23/T9/Line2300)
	Changing perspectives	Jasmine: "Sometimes you'll be saying something to him and then you realize he's doing what he can and you give him the benefit of the doubt…Then, you might switch the way you're saying it to him. I think that's been extremely helpful." (22/T9/Line1234)
	Learning information about the disability and resources in the community	Terry: "There is lots of information and resources that get shared. It's just impossible to know everything, right? And so as time goes on, you just learn more and more about what's available out there." (23/T9/Line2473)
	Social connection and feelings of belonging	Jasmine: "It's a great outlet. It's just so great to go and hear other people talk about other things, to get ideas, and to be with like-minded people that aren't going to judge, because you're all in the same boat. You all get it, you know, and you don't have to worry about people with these preconceived notions about FASD. It's just a good place." (23/T9/Line2461)
	Opportunities to hear and share experiences	Janelle: "It's like the worst feeling, but then you hear six other people say that they're kid does it too, and then it doesn't seem so bad." (25/T2/Line1303)
Differences	Providing advice	Janelle: "I like listening to other people, what they have to say, and giving my two cents somewhere."

			(25/T2/Line1492)
		Differentiation of behaviours	Jasmine: "Something pops up and [the facilitator] will go, 'You know, my 'normal' kids' do the same thing…'" (22/T9/Line1338)
		Usefulness of the group based on child's age	Janelle: "We talk on the phone a lot and she's really good. Her daughter, who's four, and so she has some problems with her daughter that I have with Sarah." (25/T2/Line2301)

Table 9 continued.

		Logistical elements	Terry: "Every second week would almost be kind of nice at times, but yet then I think it might get to a point where I don't have this much time, and you start missing. Where as once a month seems manageable." (23/T2/341)
Barriers			
	Similarities	Difficult interactions with others	Janelle: "It kind of bothers me when people come into the support group…and they almost start preaching. Like 'this is the way you should do it'… It's not fair to preach to people." (25/T9/Line660)
		Childcare and timing	Janelle: "I'd even go if it was twice a month. I'd go all the time if it was in the evening. It would be nice to like have it in the evening, and have somebody there to watch the kids." (25/T2/Line150)
		Information sessions not specific to FASD	Jasmine: "She didn't seem to have anything prepared. Why are we listening to this?" (22/T9/Line1900)
	Differences	Continued feelings of isolation and lack of social connection	Jasmine: "I still feel lonely, oh yeah. Still sometimes, you know, it's like will this ever end?" (22/T9/Line2166)
		Difficulties with facilitation	Terry: "It often seems like it takes a bit to get started, to get people to open up, and I don't know if you could change that. Maybe one thing that could happen is if moderators, facilitators, whatever, had one topic that they started along that maybe spearheaded some more of the conversation. Like something they encountered or unique story that they encountered that would just kind of get people rolling a little bit easier." (23/T9/Line2385)

more positive outlook. Rather than remaining stuck in the day-to-day struggles, they all tried to focus on what was going right in their day-to-day lives as well as how far they had come as a family. Jasmine, Terry, and Janelle benefitted from observing the improvement of other caregivers over time. Receiving information about FASD as well as helpful resources in the community that they could access without difficulty was also helpful. It gave them additional tools to address the difficulties they were experiencing at home, while also changing their expectations of their son or daughter's behaviour and creating hope for the future by broadening their support networks.

Additionally, Jasmine, Terry, and Janelle all reported the helpfulness of the social connection with other caregivers in the group and feeling as if they belonged in the group. Their participation reminded them of the universality of their experience, which decreased their feelings of isolation and burden. Social connection was particularly important for Terry and Janelle who connected with other participations outside the group for further collaboration and support. Feelings of community were developed through the ongoing opportunities to hear and share experiences, which helped caregivers to unburden emotions. It was particularly important to be able to express these stories with caregivers whom largely understood their experiences in an environment that was respectful and nonjudgmental.

Despite these commonalities, some benefits were specific to individual cases (see Table 8 for an overview and Table 9 for illustrative examples). Some aspects that were highlighted as benefits were not common to all cases. This included: (a) Providing Advice; (b) Differentiation of Behaviours; (c) the Usefulness of the Group Based on the Child's Age; and (d) Logistical Elements. For Janelle, the opportunity to share what she had learned by providing advice or a range of suggestions was helpful for her to feel confident as a parent, and reminded her of how far she and her daughter had come. For Jasmine and Terry, this was not a particularly helpful aspect for them. Jasmine's understanding of the difference between developmentally appropriate behaviour versus behaviour that could be better attributed to the effects of FASD was particularly helpful. Members of the group often helped to differentiate this for Jasmine by providing information from their own experiences. Furthermore, the benefits of the group were somewhat a function of the developmental stage of their son or daughter. For Terry, it was helpful to have adoptive caregivers in the group with older children to remind her of the universality of her experience and instill hope. For Janelle, it was helpful to have another caregiver, with whom she connected, that had a daughter the same age. Jasmine's teenage son was one of the oldest in the group; however, Jasmine obtained benefits from hearing the stories of caregivers of other teenagers in the group. Comparing her son's behaviour to that of others in the group helped her to focus on his positive behaviour. Finally, while Jasmine and Terry appreciated the group being monthly, Janelle indicated she would benefit from more frequent sessions.

There were also similarities among caregivers' experiences of barriers across individual case studies (see Table 8 for an overview and Table 9 for illustrative examples). Similarities included (a) Difficult Interactions with Others; (b) Childcare and Timing; and (c) Information Sessions Not Specific to FASD. Both Janelle and Jasmine had negative interactions with other caregivers in the group. Both Janelle and Jasmine had previously indicated they would like additional participants to attend the group; however, when new caregivers attended the group, and did not adhere to the social norms of the group, it was problematic for them. At times, members would "take over" or monopolize the discussion. Childcare was another barrier for all caregivers. Caregivers were able to attend for different reasons (i.e., maternity leave, worked from home, underemployed), but all indicated they would appreciate if childcare were provided for an evening support group in the event that they could no longer attend during the day. Finally, all caregivers indicated that although the majority of information sessions were helpful, particularly information related specifically to FASD, some information sessions were inapplicable, dull, or were not a service that they could access.

Differences in caregivers experiences of barriers to attending the group included: (a) Continued Feelings of Isolation and Lack of Social Connection and (b) Difficulties with Facilitation. Jasmine in particular indicated that it was difficult for her to maintain feelings of community and universality of experience past her attendance of the group. Instead, she often became discouraged and isolated when at home. This was not necessarily a unique experience, but it was particularly prominent for her. Finally, Terry also indicated that at times the beginning of the psychoeducational support group sessions could be particularly slow, which was collaborated by observations of the group. Her suggestion of having a particularly theme, topic, or story to get the group going may be particularly helpful.

CHAPTER FIVE

Discussion

Three caregivers participated in the current study and provided information regarding the impact of participating in a psychoeducational support group for caregivers of children diagnosed or suspected of having FASD. This chapter focuses on an interpretation of the findings: (a) information on the individual experiences of caregiver stress, sense of competence, social support, and quality of life (i.e., individual case studies for Research Question A), (b) caregivers' individual experiences of the psychoeducational support group (i.e., individual case studies for Research Question B), and (c) a comparison of these experiences across three multiple cases (i.e., multiple case study for Research Question C). Each participant provided a unique perspective. Concise summaries and interpretation of the findings are presented with evidence from the study, as well as a discussion of these findings within the context of previous literature. An overview of "lessons learned" is also outlined under practice and methodological implications, which builds upon the interpretation of the findings. Finally, study limitations and recommendations for future research are reviewed.

Research Question A: A Priori Factors

Deductive analysis of a priori factors of caregivers' experiences revealed several themes for each individual caregiver related to levels of stress, sense of competence, social support, and quality of life while (or after) participating in the psychoeducational support group. Both quantitative and qualitative sources provided valuable information for the individual case studies, but in different ways. Data collected through questionnaires provided information regarding each caregiver's experiences of these factors; nevertheless, questionnaires often did not capture the nuances and contextual information of these experiences. Interviews and other qualitative strategies further illuminated and elaborated as the themes that were salient for each individual. A review of the a priori categories across caregivers suggests some similarities and differences, which are compared for the multiple case study for Research Question C. An interpretation for each individual case study is presented.

Feelings of stress arose as an important factor for all caregivers involved in the study, and questionnaire data reiterated the high levels of stress experienced by caregivers of children with FASD, both before and after the intervention, which is consistent with previous research (e.g., Watson et al., 2013). Sources for caregivers included individual, family, and external sources, which often fluctuated throughout the course of the study. Caregivers reported that their participation in the psychoeducational support group was helpful for decreasing their feelings of stress, as well as for increasing their feelings of confidence and social support. However, these changes were not reflected in questionnaire data. It may be that caregivers are inaccurate reporters of their own levels of stress and related factors. Alternatively, and more likely, questionnaires were not sensitive to detect such changes for this caregiver population that research has shown experience high levels of stress (i.e., ceiling effect). Nevertheless, both qualitative and quantitative information was important for gathering a more complete picture of caregivers' experiences of the psychoeducational support group.

In addition to the group, reported changes in feelings of stress were also linked to family and external factors, such as relationships with educational institutions, extreme behaviour, and financial stressors; therefore, reported changes in stress levels may not be a direct result of participation in the intervention. Understanding these internal and external factors is important for designing and implementing beneficial and effective caregiver groups, but also to help ameliorate undue external factors through advocacy and connecting families to appropriate resources as needed.

For Jasmine, several sources of stress emerged in addition to the ways the psychoeducational support group impacted her level of stress as a source of support. Both the quantitative measures (PSI/SF and CFS) indicated Jasmine was experiencing significant amounts of stress, both before and after the intervention. Themes that emerged through analysis included chaos in the household, Logan’s lack of friendships and social skills, being uncomfortable with using respite services, experiences with the school system, dealing with issues of guardianship, and her son’s and daughter’s behaviour (such as sneaking food) were all sources of stress for Jasmine. Jasmine’s responses in questionnaires did not reflect any considerable decreases in stress; however, Jasmine reported in interviews that her stress decreased somewhat for a few reasons. Overall, quantitative measures were not sensitive enough to illuminate changes in stress levels over time (discussed in more detail under Methodological Implications). Logan was displaying more mature behaviour, Logan was accepted into a specialized high school program, and Jasmine had increased her involvement with respite services. The group also impacted Jasmine’s stress in several ways, including providing the time to reflect on Logan’s strengths (which was helpful for Jasmine at home and at the group), providing resources and strategies for both Logan and his siblings, increasing her parental knowledge, and reducing her isolation, if only briefly.

An analysis of Jasmine’s feelings of parental sense of competence revealed five themes: positive reinforcement, patience, parental knowledge, reassurance, and strategies. In particular, Jasmine’s connection with the group helped her to increase her parental knowledge and knowledge of services, and provided needed reassurance. The group also provided support for Jasmine, along with her parents, sister, her husband Clarence, and the Coaching Families program, but she sometimes continued to feel isolated and alone after the group was finished. Overall, Jasmine's overall quality of life was positively impacted by her involvement with the group, and learning about strategies and techniques, as well as her involvement with respite programs, that allowed her to have some flexibility and independence since she often could not travel with Logan.

For Terry, data analysis revealed several sources of stress during the study, as well as ways the psychoeducational support group impacted her level of stress. Over the course of the study, Terry's stress fluctuated as a result of Tyson's behaviour; however, quantitative measures (PSI/SF and CFS) indicated Terry was experiencing significant amounts of stress before and after the intervention, again suggesting that quantitative measures did not detect smaller changes in caregiver stress levels. Themes of sources of stress for Terry included: lack of sleep, her son's extreme behaviour and constantly having to monitor his behaviour, the newness of the experience, people trying to help that are unhelpful, and transitioning back to work. Terry frequently worried about the future and whether Tyson's aggressive behaviour and outbursts would continue. These worries were reflected in Terry's responses on the PSI/SF, which indicated she was experiencing significant amounts of stress compared to other caregivers. Despite these results, Terry's perception of her own stress was reduced. The psychoeducational support group helped Terry with her stress because it instilled hope, reminded her of the universality of her experience, and imparted information, which are common benefits for participants. In particular, receiving guidance and advice from others often helped to address Terry's stress.

Like most parents, Terry had doubts about whether she was doing the "right thing." However, Terry felt relatively confidence as a parent, despite the newness of this role, and this was reflected in Terry's responses on the PSOC. Terry attributed her confidence to several things, including themes related to: her acceptance and willingness to learn, willingness to dedicate time, adapting as needed, preventing behaviours from escalating, and feeling knowledgeable as a parent. Terry's responses on the PSOC also suggested Terry was more confident as a parent than satisfied, which may reflect high levels of frustration and anxiety as a parent, and therefore, is likely related to her high levels of stress and the "newness" of the situation. Terry's connection to the group provided information and guidance for her new role. The group also provided social support for Terry, along with her sister-in-law, pediatrician, friends, and the school system. Terry made connections with other caregivers in the group that she extended beyond the sessions. Overall, despite the stress she experienced related to his behaviour and worrying about his future, Terry indicated her quality of life had drastically increased since the adoption of her son.

For Janelle, the quantitative sources (PSI/SF and CFS) suggest she was experiencing significant amounts of stress compared to other caregivers. Overall, Janelle reported during interviews and feedback forms that her stress increased over the course of the study, although again the questionnaires did not capture this change. Several sources were contributing to this stress, including a strained relationship with her daughter's school, side effects from medication that her daughter began taking during the study, being laid off and attempting to find a flexible job where she could continue to bring Sarah to her appointments, dealing with extreme behaviour, and dealing with the added stress of having others judge her daughter's behaviour. Social support appeared to be the most important factor for Janelle to deal with significant amounts of stress. The psychoeducational support group helped with this aspect. Janelle indicated she benefited from talking with other caregivers, and even preferred to have additional opportunities for discussion, rather than attending information sessions. To Janelle, the information sessions were not as beneficial.

Janelle indicated she has always had an interest in parenting and parenting approaches. She indicated she feels fairly competent as a parent, and her responses on the PSOC reflect these feelings, both for efficacy and satisfaction with parenting. Themes of understanding, willingness to learn, patience, parental knowledge and strategies, and advocacy skills all contributed to Janelle's feelings of self-efficacy as a parent. Janelle valued being able to share her own perspectives, strategies, and resources at the group, which helped to expand her own parental efficacy. The group also provided her with social support, along with her friends, parents, and professional organizations. Janelle made a connection with one particular caregiver in the psychoeducational support group. They would often talk on phone when they needed support and advice. Overall, Janelle indicated she had a high quality of life, despite difficulties with financial resources.

An examination of each caregivers' experiences of stress, sense of competence, social support, and quality of life reveals similar and varied themes (discussed in more detail under Research Question C). Caregivers' stress reportedly decreased, and their social support and sense of confidence both reportedly increased, during their participation, but this was only reflected in qualitative data sources, and may reflect the influence of external factors. Understanding the contextual experiences of each caregiver, including characteristics and experiences of raising a child with disabilities, interpretations and making of meaning of situations, resources, supports, and self-appraisals available to the family, as discussed in the Contextual Model of Stress (Boss, 2002), are important for the success of a group caregiver intervention, as each caregiver bring unique experiences to the group. As the first case revealed, Jasmine required opportunities to reflect on her experiences in order to decrease her daily stress of raising a child with FASD, as well as help develop her low sense of confidence as a parent. In comparison, despite Janelle's age, she felt relatively confident in her parenting strategies, but needed opportunities to share her experiences about her successes and to share her challenges with people that understood; social support was of primary importance for her. Finally, as a new parent, Terry needed to hear advice and learn about resources in the community, as well as help envisioning a positive future. Therefore, a needs assessment by a skilled facilitator that gathers information at different time points regarding these internal, external, and bidirectional factors would be helpful for targeting support and information as needed (discussed under Practical Implications).

Research Question B: Individual Experiences of Psychoeductational Support Group, Including Benefits and Barriers

Each case provided information regarding the individual benefits and barriers for participation in the psychoeducational support group, gathered through interviews, feedback forms, and rating scales, to form individual case studies. An overview of themes of caregivers' experiences can be found in Table 4 (p. 165). Each of the participants reported their own personal benefits to participating in the psychoeducational support group. Often benefits were unique to particular caregivers, give their context, previous experiences, and the length of time they had been caring for a child with FASD. The process of the interview allowed for reflection to occur and for the participants to think about what they found most valuable.

For Jasmine, data analysis revealed four benefits of attending the psychoeducational support group. First, Jasmine often reiterated that the group helped her to shift her perspective and appreciate the positives and focus on her child's strengths, as well as enabling Jasmine to focus on her own strengths as a parent. Even when Logan was struggling at school, Jasmine often left the group with a better appreciation for all the things that her son was capable of, due to caregiver stories about much more extreme behaviour. It reminded Jasmine of Logan's capabilities and provided information to Jasmine about supports in the community. It helped her to expand her vision of her son's future. Second, the group helped Jasmine to distinguish between what is typical for a youth his age and what behaviour could be best attributed to FASD. Through hearing stories and receiving feedback from other caregivers, Jasmine realized that much of the behaviour that Logan was exhibiting was to be expected. Third, as noted in the previous benefits, the group provided an opportunity to share ideas and receive feedback, which also reminded her that she was not alone. Fourth, Jasmine learned about strategies and resources through her participation in the group. For example, Jasmine learned she was not focusing enough on the positives and she began trying to use positive reinforcement at home.

Despite these benefits, participants also identified unique barriers to their experiences and participation. Three barriers arose for Jasmine as she attended the group. First, although Jasmine indicated she felt a connection with other caregivers, and that the group helped her to feel less alone, this feeling often did not last for Jasmine. Once she left the group she once again felt lonely and isolated. This may suggest the need for additional services for caregivers above and beyond the psychoeducational support group, such as the larger *Coaching Families* or other services that support caregivers in dealing with their day-to-day stresses and isolation. Second, some of the interactions that she had with other caregivers at the group were less than positive. The majority of time caregivers were respectful and responsive to one another. However, on a few occasions some participants that dropped in for the support group made Jasmine uncomfortable as she felt these new participants judged her. Jasmine felt the dynamic was drastically changed in these instances, which hindered the benefits of the group for her. Third, although Jasmine appreciated many of the information sessions because it often provided information about services, some of the information sessions were less helpful for Jasmine due to poor facilitation of the sessions. This reiterates the need for skilled facilitators for caregiver groups.

For Terry, data analysis revealed three particular benefits. First, the group helped Terry to make connections with other caregivers who were experiencing similar difficulties. These connections with other participants extended beyond the group. Second, the group helped Terry to envision a positive future for herself, her son, and her family, instead of a big unknown. Third, Terry quickly learned about resources in the community both for what she needed now, but also for the future. At the commencement of the study, Tyson had been living with Terry for two months. Tyson's behaviour escalated throughout the course of the study. Tyson was defiant and physically aggressive. Terry worked hard on employing a token behaviour management system at home. Terry began her involvement with the group shortly after adopting Tyson once the "honeymoon period" was over. She had learned about the group from another community mental-health agency when she advocated for additional services. Terry had also been put on the Coaching Families waitlist at that time. She was assigned a mentor half-way through the study.

There were two barriers for Terry to attend the group, despite the benefits of the group. First, at times the group was slow to start, as everyone seemed hesitant to share their experiences. Terry suggested a topic be selected or an icebreaker activity be introduced in order to speed this process along. Second, Terry began working part-time part way through the study and could not attend some sessions, which was also a barrier for several other participants. It was hoped in the future that additional times for support group sessions could be introduced. This is a common struggle for caregivers attending groups, and finding a time that works for most is key.

Two particular benefits for participating in the group were identified for Janelle (see Figure 27). The first beneficial aspect for Janelle appeared to be bidirectional: her own process of hearing stories from others and building up her own self-efficacy by providing strategies to others. Second, Janelle learned from the group that she had to change her expectations of Sarah if they were going to be successful. After some time, she reported she finally understood that some of negative effects from the alcohol exposure were irreversible.

Finally, two barriers to Janelle's participating were also identified. First, some of the interactions that Janelle experienced with some caregivers that were not regular attendants were less than positive. In some cases, these negative interactions could have been redirected through skilled facilitation. At the beginning of the study, Janelle was advocating for the group to expand and enlarge in order to accommodate additional caregivers; however, after experiencing some negative interactions, Janelle felt it was best to keep the group small with core members. Second, some of the information sessions were not beneficial for Janelle, as some did not touch on particular topics that were relevant to her.

As previously stated, a paucity of research has been conducted on support groups with caregivers with children with FASD. Nevertheless, Shepard and colleagues' (2012) investigation exploring caregivers' experiences of attending a camp for caregivers of children with FASD also found acceptance and understanding, as well as acquiring information and tools, to be benefits, which was also reiterated in the current study. Moreover, several benefits highlighted in one unpublished Masters Thesis investigating the experiences of caregivers of children with FASD participation in support groups were reproduced by the current findings (Porty, 2009). In Porty's (2009) previous exploration, caregivers valued the understanding, respect, and acceptance they found at the support group, as well as the opportunities to talk about their experiences and to learn from others' experiences, which helped them to feel less isolated. They appreciated the opportunity to reframe their child's behaviours, as well as receive education about their child's disability. All of these findings were reiterated in the current findings.

In contrast, Porty (2009) reported caregivers also experienced the negative impact of hearing horror stories from other caregivers. This was not the case in the current study, as all of the caregivers had reframed these experiences to focus on the positives found in their child's behaviour or the relationship they had with the son or daughter. This may have been a function of the age or developmental stage of the children that had participated in the study. Rather than seeing a negative future with many stressors, caregivers made direct comparisons in the present and reframed their own perspective. Alternatively, there were many examples of positive success stories shared by caregivers in the group that may have counteracted the negative effects of such shared experiences. All the same, two caregivers reported the negative impact of the inclusion of new members in the group, particularly of problems members that monopolized the conversation, rejected the opinion or perspective of others, and did not adhere to the established group norms.

Research Question C: Cross-case Comparison for Multiple Case Study

In order to draw upon similarities and differences of caregivers' experiences of participating in the psychoeducational support group, cross-case comparisons occurred for caregivers' experiences of a priori categories, as well as caregivers' individual experiences that arose through inductive analysis. Cross-case analysis revealed caregivers were experiencing significant amounts of stress throughout the study (compared to the normative sample of the PSI/SF). Caregivers' stress levels fluctuated based on numerous life stressors, either positively or negatively. Despite these difficulties, all caregivers reported the psychoeducational support group helped to reduce their stress in a number of ways, and could provide specific examples of how this had been accomplished. Additionally, all caregivers indicated the psychoeducational support group was also helpful for increasing their confidence as a parent and amount of social support. All caregivers' sense of competence was influenced in different ways by their involvement with the group. Caregivers indicated that their knowledge had increased as a result of participating in the group, but this did not translate into feelings of efficacy for all caregivers. One caregiver indicated she felt confident of her parenting skills prior to her involvement with the group, despite it being a new experience for her. Although the degree of support varied between individuals, all caregivers indicated areas of social support that were helpful for them, and this was positive affected by their association with the group.

The current study provides information regarding how participating in the psychoeducational support group impacted caregivers' feelings of stress, sense of competence, social support, and quality of life, although this was primarily gathered through qualitative reports as the questionnaires were not always sensitive enough to pick up on changes over time. However, it is unclear if the current psychoeducational support group provided enough encouragement and support to facilitate increased feelings of parental sense of competence and support, and decreased stress, in order to influence parenting practices, strategies, and behaviours (Coleman & Karraker, 1998), as that was out of the scope of the current research project. Nevertheless, the findings of the current study suggest similar gains may be found for support groups for caregivers of children with FASD comparable to what previous research has found for other caregiver populations. Previous research has suggested that group caregiver interventions, including support groups and training sessions, for caregivers of children with disabilities have helped to decrease caregiver stress (e.g., Bohjanen, Humphrey, & Ryan, 2009; Pisterman et al., 1992; Singer, Ethridge, & Aldana, 2007), increase caregivers' sense of competence or self-esteem (e.g., Bailey, 2007; Dunst, Trivette, & Hamby, 2007; Hautmann et al., 2009; Liu, Chao, Huang, Wei, & Chien, 2010), and increase family social support (e.g., Marcynyszyn, Maher, & Corwin, 2011), all of which promotes positive parenting practices and enhances caregiver-child interactions (Coleman & Karraker, 1998). Support groups for caregivers with children with disabilities have been found to help develop a sense of control and agency (e.g., Solomon, Pistrang, & Barker, 2001) and feelings of empowerment following their child's diagnosis (e.g.,Banach, Iudice, Conway, & Couse, 2010).

Additionally, from the multiple case study, all individual cases experienced some similar benefits and barriers to attending the group, many of which have been previously documented in other literature associated with the positive outcomes of support groups and group interventions. Cross-case analysis of caregivers' experiences revealed five salient themes of benefits associated with attending the psychoeducational support group: feelings of hope, changing perspectives, learning about disability-specific information and resources, creating social connections, and opportunities to hear and share experiences. Yalom and Leszcz (2005) have outlined 11 interdependent factors that thought to be helpful for the positive outcomes associated with group based interventions and support groups (see Chapter 2). A comparison of these 11 factors to the five themes derived from both quantitative and qualitative data reveal some overlap and similarities. More specifically, six out of the 11 factors relate to the current multiple case study: (a) the instillation of hope; (b) the universality of experience; (c) imparting didactic information and direct advice; (d) altruistic behaviour; (e) catharsis release of emotional tension; and (f) group cohesiveness and feeling apart of the group. These factors can be grouped based on cognition, behaviour, social, and emotional processes. Nevertheless, as Yalom and Leszcz (2005) attested: “No explanatory system can encompass all of therapy. At its core, the therapy process is infinitely complex, and there is no end to the number of pathways through the experience” (p. 21).

As previously stated, Yalom and Leszcz (2005) have suggested that hope is the most important factor for the effectiveness of support groups. Hope is required for the continued attendance by participants as well as for the belief that participation in the process may be effective for change. This has been reiterated by the current findings, as well as one prior study investigating caregivers’ experiences of attending a camp for caregivers of children with FASD (Shepard, O'Neil, Down, & Morris, 2012). To all members, participating in the intervention was beneficial for becoming more hopeful about their son or daughter’s future, a belief that their involvement in the group was beneficial on several levels, and learning from others about the improvement of situations over time. Additionally, hearing the stories of other caregivers regarding analogous feelings and experiences, and being accepted by the group in these experiences, decreased feelings of isolation and remoteness. Moreover, all caregivers reported they benefited from the advice and perspectives of others, as well as the information shared during information sessions. Also, one caregiver in particular benefited from the opportunity to share pieces of advice in improving her own sense of confidence. Caregivers also reported of the benefits of sharing their experience, not only for receiving others’ advice and perspectives (which is necessary for a beneficial experience), but also for the emotional release that provided to sharing it with people that understood their situation. Finally, all caregivers also reported the importance of feeling apart of the group and the support that afforded them. Yalom and Leszcz (2005) specified that early group cohesion is important for group interventions. It is hypothesized that this is why the psychoeducational support group, facilitated by the *Coaching Families* team, has been so well attended in recent years in comparison to prior iterations.

The results of the study indicate caregivers' experiences of participating in the psychoeducational support group included more similarities than differences when compared across three cases. Generally, all three caregivers had positive experiences of participating in the group, although their experiences were mediated by different factors. Benefits for attending the group included increased feelings of hope, creating social connections between caregivers, and learning about FASD-specific information and resources for caregivers. The combination of a supportive structure with information appeared to be beneficial for all. Caregivers' experiences of the group were particularly related to their feelings of stress, which arose as a dominant theme in interviews, questionnaires, observations, and feedback forms. All caregivers indicate the group was helpful for decreasing their levels of stress, although all caregivers had significantly elevated levels of stress overall. All caregivers reported several sources of stress and two sources of stress were common across cases. All caregivers experienced stress related to their children's extreme behaviour, and in two cases (i.e., Terry and Janelle) experienced stress related to negative experiences related to the school system. The third case (i.e., Jasmine) reported their stress decreased largely because their son was accepted into a specialized high school program. These results cannot be generalized beyond the experiences of these three caregivers; however, these results suggest the possibility for others to experience similar sources of individual, family, and environmental stress and related factors.

The subject of stress was dominant for all, but secondary factors, including sense of competence, social support, gaining knowledge and information, and looking to the future, differed across the three cases. These results suggest facilitators for group interventions for caregivers can play a critical role for caregivers. Prompting by facilitators can help caregivers recognize the factors that play a role in their own experiences. Caregivers experience different pressure points, but the process of moving forward can often follow a similar path. These results suggest it is helpful for caregivers to be critical and reflect on their own experiences in order to move forward. Due to these differences, caregivers and facilitators need to know and reflect individual experiences in order to create an intervention that be helpful and appropriate to a range of needs. To address the diverse needs of caregivers, these results suggest combining both opportunities for support and providing information, along with creating a cohesive group, was important for helping a range of caregivers. Additionally, these results suggest that group interventions are not necessarily sufficient for caregivers in order to address clinical levels of stress, but may be a cost effective strategy for helping caregivers be reflexive about their experience, create social connections, and learn information about FASD.

Finally, the current study also generally reiterated the beneficial aspects of having the sessions monthly at a convenient location with a skilled facilitator was important, despite one caregiver believed having the sessions more frequently may also be beneficial. Providing childcare would also help to facilitate continued attendance. Access to childcare and the timing of the sessions, having difficult interactions with new members to the group, and a lack of connection to some information sessions were also common across cases, which is supported by previous research. One caregiver reported continued feelings of loneliness and isolation outside of the group, and another caregiver suggested the facilitation of the group could be improved; however, this was not common to all cases.

Practice Implications

In addition to the beneficial approach of including both support and information components for the intervention, five lessons learned are identified based on the results of the study: (a) the benefits of a needs assessment for caregivers; (b) the value of a knowledgeable facilitator; (c) the importance of group cohesion and the inclusion of a range of caregivers; (d) the necessity to remove barriers for attendance, including providing child care; and (e) the need to provide access to additional services for caregivers, such as respite programs. It is hoped that the findings from this research study will help identify what aspects of the intervention were helpful and impactful for the caregivers who participated, which may help to inform future FASD group intervention programs for caregivers.

All caregivers talked about the benefit of learning additional information about FASD and the resources that were available in the community for their family. However, some of the information sessions provided to the group somewhat missed the mark in terms of providing information that were meaningful to caregivers, although pairing information with support was reportedly helpful for all caregivers. Some feedback was solicited from the group regarding what information was desired, having a more formal method for determining the needs of group may be helpful to best determine what information sessions would be the most beneficial to caregivers. Polling caregivers as to what would be most beneficial for them to learn about during the information sessions, as a type of needs assessment, would be a straightforward initial step of aligning program objectives with caregivers' needs.

Additionally, each caregiver in the current study brought their own contextual factors to the group. For example, Terry had only recently adopted her son, whereas Jasmine had been a caregiver for several years, which suggests they are at different stages in their caregiving. Information from Jasmine and Janelle suggested they were currently collaborating with professionals, while Terry was beginning to gather information related to FASD (Walls & Pei, 2013). Understanding the contextual factors, and stages of caregiving, is helpful for modifying the program in order address the needs of each caregiver. Having regular interviews as part of the intervention process, regardless of their involvement in the *Coaching Families* program, would be beneficial for learning more about each caregivers' sources of stress, level of social support, or feelings of confidence. Interviews held annually or biannually may be feasible and frequent enough to learn more about caregivers.

Caregivers spoke highly of the facilitators, which is incongruent with previous research. One previous study investigating the benefits of a support group for caregivers of children with FASD highlighted the need for knowledgeable and skillful facilitators for increasing the effectiveness of the group (Porty, 2009). Only minor suggestions were provided regarding the facilitation of the current psychoeducational support group, including having an opening activity to avoid the slow start up of the group. Caregivers' attendance at the psychoeducational support group may be a testament to the skilled nature of the facilitators, who often drew on their knowledge of FASD from working with caregivers and their involvement with a group home for individuals with FASD. Continued facilitation of the group with a knowledgeable facilitator, who knows the participants and their context, is necessary for the group's continued success.

The current group benefitted from the range of caregivers that attended the group. Some caregivers were in the process of adopting a child with FASD, had recently adopted a child, or had been a caregiver of a child with FASD for many years. Additionally, caregivers had children from a range of developmental stages. Having the opportunity to share successful experiences, particularly from caregivers who had raised children for many years, provided hope to many other caregivers. Alternatively, hearing from caregivers taking care of children of similar ages was also beneficial to remind caregivers of the universality of their experience. Having caregivers share success stories helped to ameliorate the possible negative impact of "horror stories", which had been found in other research to be a detrimental impact of participating in such a group (Porty, 2009). Group cohesion and feelings of belongingness were highlighted as a key benefit for caregivers participating in the group. Developing connections with other caregivers through the discussion of shared experience was particularly important. This factor is reiterated in Yalom and Leszcz's (2005) work highlighting the interdependent factors that are thought to be helpful for positive outcomes associated with participation in the group. Establishing this group cohesion early on in the process of a psychoeducational support group would be particularly beneficial, and is likely one of the reasons of the success of the group of the current study.

All caregivers in the multiple case study were able to attend the group during the morning (i.e., working from home, maternity leave, underemployment); however, all caregivers indicated having childcare, particularly if the group were to be held in the evening, would be helpful for attendance. It is likely that other caregivers are unable to attend due to the lack of childcare available. Childcare would help improve group attendance at similar caregiver group intervention. Additionally, holding multiple sessions at varying times (e.g., afternoon and evening) is one way to increase the number of families that can attend.

Despite the benefits of attending the psychoeducational support group, additional services are necessary for caregivers of children with FASD. As the current study attests, caregivers with children with FASD experience significant amounts of stress, and having additional services is important to ensure the positive outcome of children with FASD. In the current study, caregivers highlighted the importance of their involvement in the Coaching Families program and the individualized support that provided, as well as having access to respite services.

Findings from this research will be communicated through various knowledge sharing activities in collaboration with *Coaching Families* (see Appendix A). The findings of the psychoeducational support group were shared with *Coaching Families* through a short executive summary and presentation, as well as at various conferences. Caregivers, service providers, practitioners, parent educators, and decision makers may benefit from the information provided from this study by adding to the literature of how to best serve the needs of caregivers of children with FASD.

Methodological Implications

In this instrumental multiple case study, studying the quintain of caregivers' experiences of a psychoeducational support group was dominant. The quantitative data collection, analysis, and interpretation arguably enhanced and augmented by the collection of secondary qualitative data, and the integration of both strands through joint displays (i.e., matrices), cross-case comparisons, and narrative (weaving). As Yalom and Leszcz (2005) stated: "Paper-and-pencil or sorting questionnaires provide easy data but often miss the nuances and the richness of the clients' experience" (p. 23). Although the questionnaire provided rich and insightful information regarding caregivers' experiences, they were not sensitive enough to pick up on change throughout the study. Thus, the additional qualitative information was helpful to augment and integrate with this information. Future program evaluation of similar programs, both with large and small sample sizes, may also find the addition of qualitatively derived information helpful for documenting and addressing change that cannot be captured by standard questionnaires.

Integration has been recently highlighted to be the key benefit of mixed methods by key researchers (e.g., Fetters & Freshwater, 2015). For the current study, it was important to collect and integrate both types of data in order to provide a clearer clinical picture for each case. For each research question, the integration of quantitative and qualitative data provided an enhanced understanding. For example, the collection of quantitative and qualitative pieces of information provided *discordant* findings (as described by Fetter et al., 2013) when comparing levels of stress experienced by caregivers. Comparing these pieces of information provided a new and negotiated discussion of the findings. Additionally, the qualitative findings *expanded* the understanding of caregivers' sense of competence, providing a more comprehensive understanding of their experiences. Furthermore, qualitative data *confirmed* several themes of benefits and barriers of participating in the group. A comparison of these findings across cases reiterated the importance of both sets of data, as well as reaffirmed the valuable tradition of collecting both qualitative and quantitative information in the practice of clinical and school psychology (Powell et al., 2008).

Participation in the current study also appeared to give caregivers the time and space to reflect on their own caregiving experiences and involvement in supportive programs. By participating in the research project, participants spent time reflecting on their journeys as caregivers through interviews, feedback forms, as well as completing questionnaires. For caregivers, most notably Jasmine, having the time to reflect helped to relieve feelings of stress through putting her experiences within a larger perspective, rather than being "stuck" in the day-to-day struggles of raising a child with FASD, which helped her to deal with feelings of stress and was a benefit for participating in the group.

Despite the benefits resulting from the integration of both qualitative and quantitative data within a CBRE framework, as a student with experience in primarily observational quantitative research, the current study was a large departure. Taking on two additional new methodological approaches, mixed methods *and* CBRE, was at times particularly difficult. It reiterated the challenge of lack of expertise for mixed methods research (Creswell & Plano

Clark, 2011) and the importance of mentorship and guidance throughout the project. Additionally, it corroborated the finding that mixed methods can quickly become an unmanageable size (Stake, 2006). For example, the interview questions could have been more focused on particular critical incidents that had occurred during psychoeducational support group sessions, and less on the contextual factors of each case.

Several prominent researchers and theorists in the area of mixed methods have discussed the issue of methodological rigor and the process of evaluating mixed methods studies (Dellinger & Leech, 2007; O'Cathain, 2010; Onwuegbuzie & Johnson, 2006). O'Cathain (2010) has provided a comprehensive framework of 30 criteria for evaluating mixed methods project at each stage of the research project, based on literature reviews, researchers' perspectives, and mapping exercises with researchers. Thus, although comprehensive, Appendix U includes notes addressing each criterion grouped under nine quality domains. See O'Cathain (2010) for definitions of each item.

The current study contributes to the mixed methods discourse within the area of interventions for caregivers of children with FASD by providing an additional example of an embedded mixed methods design. There is a paucity of embedded mixed methods studies within the disciplines of clinical or educational psychology. The integration of qualitative measures into the larger quantitative framework helped to provide additional contextual information regarding caregivers' experiences. Additionally, this was completed within a CBRE framework.

Limitations and Recommendations for Future Research

There are several limitations to the current study, which should be addressed in future research: (a) absence of generalizability and causality, (b) homogeneous sample, and (c) appropriate questionnaires. The outcome of case study methodology is the throughout understanding of the particulars of a case (Stake, 2005). As a result, as with all case studies, the results from the current study cannot be statistically generalized from this particular context to other group interventions for caregivers of children with FASD (Yin, 2009). In order to address this limitation, as Stake and Trumbull (1982) suggests, thick description of the context and case for vicarious experiences was presented in order for readers to make their own naturalistic generalizations. Stake and Trumbull (1982) suggests naturalistic generalizations can be made if readers feel the findings may be applicable to similar cases and contexts. In order to address this limitation, the current study attempted to provide thick descriptions. However, caution was taken when making inferences based on the findings of the study, particularly because it has been shown that many researchers make inferences beyond the scope of their findings (Onwuegbuzie & Leech, 2010). In particular, causal inferences could not be made as a result of the case study design due to the small sample size and lack of comparison group. Future research should expand sample sizes to enhance the transferability of findings to other populations, and to corroborate research findings. Appropriate sample sizes would lend to increasing power for the statistical analysis of pre- and post-intervention change. Additionally, the inclusion of control groups would allow for making causal inferences. Nevertheless, including both quantitative and qualitative data in future will be beneficial for increasing our understanding of caregivers' experiences and including their voices. Future studies should also include a variety of participants, as the current study included a relatively homogeneous sample of adoptive mothers who self-identified as Canadian, Irish/German, and English. Including the voices of biological mothers, as well as biological fathers and adoptive fathers, will be important as they experience their own additional barriers. Finally, it is also hoped that increasing sample sizes will also increase the ability to detect changes in stress levels and related factors over time. Future research should continue to use questionnaires that are valid, reliable, and appropriate for caregivers of children with FASD, given their unique parenting context (ACCFCR, 2007).

Researcher Reflections

Qualitative research theory, particularly in the context of mixed methods research, encourages researchers to reflect upon their own values, beliefs, and practices and document their process of making decisions as the study develops (Lincoln & Guba, 1985). As a result, to promote research reflexivity, before the study began the researcher reflected on her experiences, assumptions, theoretical framework, worldview, and biases that could possibly be brought to the current research project. Additionally, throughout the data collection and analysis process, journal reflections were written as a critical reflection on biases, experiences, and challenges. Time was spent after each interview or contact with participates for reflection on the content of the interviews as well as any information that could be gathered through nonverbal communication and considering the general tone of the interaction. Time was also spent throughout the data analysis process, after transcribing information and coding analysis, reworking codes and themes. Throughout my reflections, the researcher was humbled by the information that was shared by caregivers about their experience as well as their willingness to connect with me regarding their process of participating in the psychoeducational support group. Their ability to be open about their stress, their hopes and fears, and the journey that they have experienced was undoubtedly courageous. It was a privilege to have had the opportunity to work with such resilient individuals. Being involved with this research project has largely informed my clinical work with children and their families. This research project reiterated the need to understand the larger contextual factors in a child or families' life that helps or hinders their well-being, from an ecological perspective, while approaching each family with respect, empathy, and dignity regarding each families' experiences, particularly the stressors present in their life.

Conclusion

Using an embedded mixed methods design, from the Contextual Model of Family Stress theoretical framework and the ecological systems theoretical perspective (Bronfenbrenner, 1979; 1986), the current study explored caregivers' experiences of a psychoeducational support group, including its impact on caregiver stress and sense of competence, and related factors of social support and quality of life. The psychoeducational support group was for adoptive or kinship caregivers of children with FASD and aimed to provide information and support through structured and open discussions. Six adoptive and kinship caregivers of children with FASD were recruited for a psychoeducational support group intervention and the current study. Data was collected from all six participants and three caregivers were selected for a multiple case study of caregivers' experiences of participating in the intervention. The intervention consisted of five three-hour monthly educational and support group sessions. Both qualitative and quantitative data collection procedures were used.

Jasmine, Terry, and Janelle were selected for the multiple case studies. Analysis revealed similarities and differences across their experiences. The instillation of hope, the opportunity to change perspectives, learning information about FASD and related supports, creating social connections and feeling a sense of belonging, as well as opportunities to hear and share experiences were common benefits reported by caregivers for participating in the group. Some caregivers also benefited from providing advice to other participants, which helped to boost their feelings of competence, having help to differentiate developmentally appropriate behaviour, obtaining different help based on the developmental stage of their children, as well as the desire for the psychoeducational support group to meet more frequently. Similar negative experiences were also reported, and included having difficult interactions with new members, the desire for childcare and careful timing of the group, as well as attending information sessions that were inapplicable to their experience. One caregiver reported they continued to feel isolated despite the benefits of the group. All caregivers reported they were experiencing significant amounts of stress, and that the psychoeducational support group helped to reduce their feelings of stress; however, stress levels fluctuated throughout the study based on life stressors. Caregivers also had difference experiences of feelings of parental sense of competence. For some caregivers, knowledge of FASD and parenting did not translate into feelings of self-efficacy, whereas for others, they felt confident in their role. All caregivers indicated areas of social support that could be improved in their own life, but indicated that the psychoeducational support group helped to feel connected and less isolated. In summary, the psychoeducational support group provided Jasmine the opportunity for a time to reflect, including receiving feedback from others. For Terry, the group provided an opportunity to receive information and resources that helped reduce her fear of the future. For Janelle, the group provided a needed social connection in a nonjudgmental environment that reminded her of the universality of her experience. Overall, most importantly, feelings of hope, creating social connections, and learning about disability-specific information and resources were particularly helpful for caregivers.

From the exploration of these three experiences, several recommendations for future practice are provided in order to help improve services for caregivers of children with FASD. Future psychoeducational support groups for this population may benefit from recurrent needs assessments to better understand the changing needs of participants. Secondly, a facilitator that is both knowledgeable about FASD and its effects, and is skillful in the facilitation and redirection of the discussions, is important for the continued success of the group. Helping to create a cohesive group where there is an inclusion of a range of caregivers is also important for the group’s continued success. Reducing barriers, including providing childcare for members, may also increase attendance. Finally, the results of the study reiterate the continued need for additional services for children with FASD and their families. Future evaluations of these services may benefit from increased sample sizes, as well as the inclusion of both qualitative and quantitative perspectives, for a better understanding of caregivers’ experiences.

References

Abidin, R. R. (1995). *Parenting stress index: Professional manual
 * (3rd ed.). Odessa, FL: Psychological Assessment Resources.

ACCFCR. (2007). *Measuring common outcomes for FASD intervention programs*. Calgary, AB: Author. Retrieved from http://www.research4children.com

ACCFCR. (2010). *Advancing the fetal alcohol spectrum disorder (FASD) research agenda: A compendium of research and knowledge mobilization project*. Calgary, AB: Author. Retrieved from http://www.research4children.com

Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol and Alcoholism, 35*(5), 509-519. doi:10.1093/alcalc/35.5.509

Astley, S. J., & Clarren, S. K. (1999). *
Diagnostic guide for fetal alcohol syndrome and related conditions: The 4-digit diagnostic code* (2nd ed.). Seattle, WA: University of Washington Publication Services.

Bailey, D. B. J. (2007). Introduction: Family adaptation to intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 291-292. doi:10.1002/mrdd.20168

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217-230. doi:10.1046/j.1365-2788.2003.00484.x

Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities, 30*, 194-204. Retrieved from http://tash.org/about/publications/

Baldwin, K., Brown, R. T., & Milan, M. A. (1995). Predictors of stress in caregivers of attention deficit hyperactivity disordered children. *American Journal of Family Therapy, 23*(2), 149-160. doi:10.1080/01926189508251345

Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups: A Journal of Community and Clinical Practice, 33*(1), 69-83. doi:10.1080/01609510903437383

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. doi:10.1037/0033-295X.84.2.191

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York, NY: W. H. Freeman.

Barlow, J., & Stewart-Brown, S. (2000). Behavior problems and parent-training programs. *Journal of Developmental and Behavioral Pediatrics, 21*, 356-370. Retrieved from http://journals.lww.com/jrnldbp/pages/default.aspx

Baxter, C., Cummins, R. A., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual & Developmental Disability, 25*(2), 105-118. doi:10.1080/13269780050033526

Bazeley, P. (2009). Editorial: Integrating data analyses in mixed methods research. *Journal of Mixed Methods Research, 3*(3), 203-207. doi:10.1177/1558689809334443

Belcher, H. M. E., Butz, A. M., Wallace, P., Hoon, A., Reinhardt, E., & Reeves, S. (2005). Spectrum of early intervention services for children with intrauterine drug exposure.

Infants and Young Children, 18, 2-15. Retrieved from http://journals.lww.com/iycjournal/pages/default.aspx

Belsky, J. (1984). The determinants of parenting: A process model. *Child Development, 55*(1), 83-96. doi:10.1111/1467-8624.ep7405453

Bertrand, J. (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities, 30*(5), 986-1006. doi:10.1016/j.ridd.2009.02.003

Bertrand, J., Weber, M., O'Connor, M. J., Riley, E. P., Johnson, K., & Cohen, D. (2004). *Fetal alcohol syndrome: Guidelines for referral and diagnosis*. Atlanta, GA: Centers for Disease Control and Prevention (CDC).

Bohjanen, S., Humphrey, M., & Ryan, S. M. (2009). Left behind: Lack of research-based interventions for children and youth with fetal alcohol spectrum disorders. *Rural Special Education Quarterly, 28*(2), 32-38. Retrieved from http://acressped.org/publications

Boss, P. (2002). *Family stress management: A contextual approach* (2nd ed.). Thousand Oaks, CA: Sage.

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

Bristol, M. M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the double ABCX model. *Journal of Autism and Developmental Disorders, 17*(4), 469-486. doi:10.1007/BF01486964

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22*(6), 723-742. doi:10.1037//0012-1649.22.6.723

Brown, J. D. (2004). Family supports for children who have alcohol-related disabilities. *Developmental Disabilities Bulletin, 32*(1), 44-61.

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. doi:10.1300/J039v08n03_01

Brown, J. D., Bednar, L. M., & Sigvaldason, N. (2007). Causes of placement breakdown for foster children affected by alcohol. *Child & Adolescent Social Work Journal, 24*(4), 313-332. doi:10.1007/s10560-007-0086-9

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

Caracelli, V., & Greene, J. (1993). Data analysis strategies for mixed method evaluation designs. *Educational Evaluation and Policy Analysis, 15*, 195-207. Retrieved from http://epa.sagepub.com/

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. Annual Review of Public Health, 29, 325-340. doi:10.1146/annurev.publhealth.29.091307.083824

Catholic Social Services. (2002). *FASD family stress scale*. Edmonton, AB: Author.

Catholic Social Services. (2013). FASD - coaching families program. Retrieved November 10, 2013, from http://www.catholicsocialservices.ab.ca/CSSFindServicesbyLocation/default.aspx?id=133

Centre for Community Based Research.What is community based research? Retrieved August, 11 from http://www.communitybasedresearch.ca/Page/View/CBR_definition.html

Chandrasena, A. N., Mukherjee, R. A. S., & Turk, J. (2009). Fetal alcohol spectrum disorders: An overview of interventions for affected individuals. *Child and Adolescent Mental Health, 14*(4), 162-167. doi:10.1111/j.1475-3588.2008.00504.x

Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine, 30*(11), 1161-1172. doi:10.1016/0277-9536(90)90256-R

Chronister, J., & Chan, F. (2006). A stress process model of caregiving for individuals with traumatic brain injury. *Rehabilitation Psychology, 51*(3), 190-201. doi:10.1037/0090-5550.51.3.190

Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172*(Suppl), S1-S21. doi:10.1503/cmaj.1040302

Coggins, T. E., Timler, G. R., & Olswang, L. B. (2007). A state of double jeopardy: Impact of prenatal alcohol exposure and adverse environments on the social communicative abilities of school-age children with fetal alcohol spectrum disorder. *Language, Speech, and Hearing Services in Schools, 38*, 117-127.

Coleman, P. K., & Karraker, K. H. (1998). Self-efficacy and parenting quality: Findings and future applications. *Developmental Review, 18*(1), 47-85. doi:10.1006/drev.1997.0448

Coleman, P. K., & Karraker, K. H. (2003). Maternal self-efficacy beliefs, competence in parenting, and toddlers' behavior and developmental status. *Infant Mental Health Journal, 24*, 126-148. doi:10.1002/imhj.10048

Crabtree, B. F., & Miller, W. L. (1992). *Doing qualitative research*. Thousand Oaks, CA: Sage Publications.

Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed method approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Creswell, J. W., Plano Clark, V. L., & Garrett, A. L. (2008). Methodological issues in conducting mixed methods research designs. In M. M. Bergman (Ed.), *Advances in mixed methods research* (pp. 66-83). London, UK: Sage.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Los Angeles, CA: Sage.

Crnic, K., & Low, C. (2002). Everyday stresses and parenting. In M. H. Bornstein (Ed.), *Handbook of parenting* (2nd ed., pp. 243-267). Mahwah, NJ: Lawrence Erlbaum Associates.

Cronbach, L. J. (1975). Beyond the two disciplines of scientific psychology. *American Psychologist, 30*(2), 116-127. doi:10.1037/h0076829

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability, 34*(2), 153-162. doi:10.1080/13668250902874608

Dellinger, A. B., & Leech, N. L. (2007). Towards a unified validation framework in mixed methods research. *Journal of Mixed Methods Research, 1*(4), 309-332.

Denzin, N. K. (1978). *The research act: A theoretical introduction to sociological methods* (2nd ed.). New York, NY: McGraw-Hill.

Devries, J., & Waller, A. (2004). Fetal alcohol syndrome through the eyes of parents. *Addiction Biology, 9*(2), 119-126.

Doig, J. L., McLennan, J. D., & Urichuk, L. (2009). "Jumping through hoops": Parents' experiences with seeking respite care for children with special needs. *Child: Care, Health & Development, 35*(2), 234-242.

Dunst, C. J., Trivette, C. M., & Jenkins, V. (2007). *Family support scale*. Asheville, NC: Winterberry Press. Retrieved from http://www.wbpress.com

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation & Developmental Disabilities Research Reviews, 13*(4), 370-378. doi:10.1002/mrdd.20176

Dzurec, L. C., & Abraham, J. L. (1993). The nature of inquiry: Linking quantitative and qualitative research. *Advances in Nursing Science, 16*, 73-79.

Edwards, K., Lund, C., & Gibson, N. (2008). Ethical validity: Expecting the unexpected in community-based research. *Pimatisiwin: A Journal of Aboriginal and Indigenous*

Community Health, 6(3), 17-30. Retrieved from http://www.pimatisiwin.com/online/?page_id=177

Engle, J. A. (2008). *Reinforcement learning in children and adolescents with fetal alcohol spectrum disorder (FASD).* (Unpublished Masters). University of Victoria, Victoria, BC.

Fabiano, G. A., Chacko, A., Pelham, W. E. J., Robb, J., Walker, K. S., Wymbs, F., . . . Pirvics, L. (2009). A comparison of behavioral parent training programs for fathers of children with Attention-Deficit/Hyperactivity Disorder. *Behavior Therapy, 40*(2), 190-204. doi:10.1016/j.beth.2008.05.002

Fetters, M. D., Curry, L. A. & Creswell, J. W. (2013). Achieving integration in mixed methods designs—Principles and practices. *Health Services Research, 48*, 2134–2156. doi: 10.1111/1475-6773.12117

Fetters, M. D., & Freshwater, D. (2015). The I + 1 = 3 integration challenge. *Journal of Mixed Methods Research, 9*(2), 115-117. doi: 10.1177/1558689815581222

Frels, R. K., & Onwuegbuzie, A. J. (2013). Administering quantitative instruments with qualitative interviews: A mixed research approach. *Journal of Counseling & Development, 91*(- 2), 184-195. doi:10.1002/j.1556-6676.2013.00085.x

Frey, K. S., Greenberg, M. T., & Fewell, R. R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. *American Journal on Mental Retardation, 94*(3), 240-249. Retrieved from http://www.aaiddjournals.org/loi/ajmr.1

Gardner, J. (2000). Living with a child with fetal alcohol syndrome. *American Journal of Maternal Child Nursing, 25*(5), 252-257. Retrieved from http://journals.lww.com/mcnjournal/pages/default.aspx

Giunta, C. T., & Streissguth, A. P. (1988). Patients with fetal alcohol syndrome and their caretakers. *Social Casework, 69*(7), 453-459.

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

Glosser, G., & Wexler, D. (1985). Participants' evaluation of educational/support groups for families of patients with alzheimer's disease and other dementias. *The Gerontologist, 25*(3), 232-236. doi:10.1093/geront/25.3.232

Goetze, R. (2013). Coaching families [edmonton & area]. Retrieved November 10, 2013, from http://fasd.typepad.com/fasd_support_in_alberta/2006/12/coaching-famili.html

Gold, R. (1958). Roles in sociological field observation. *Social Forces, 36*(36), 217-213. Retrieved from http://socialforces.unc.edu/

Graefe, S. (1998). *Parenting children affected by fetal alcohol syndrome: A guide for daily living.* Vancouver, BC: The Society of Special Needs Adoptive Parents.

Granitsas, J. (2004). Experiences of adoptive parents of children with fetal alcohol syndrome. *Clinical Excellence for Nurse Practitioners, 8*(1), 22-28.

Greenbaum, R. L., Stevens, S. A., Nash, K., Koren, G., & Rovet, J. (2009). Social cognitive and emotion processing abilities of children with fetal alcohol spectrum disorders: A comparison with attention deficit hyperactivity disorder. *Alcoholism: Clinical and Experimental Research, 33*(10), 1656-1670. doi:10.1111/j.1530-0277.2009.01003.x

Greene, J. (2007). *Mixed methods in social inquiry*. San Francisco: Jossey-Bass.

Greene, J., Caracelli, V., & Graham, W. (1989). Towards a conceptual framework for mixed-method evaluation designs
. *Educational Evaluation and Policy Analysis, 11*(3), 255-274. Retrieved from http://epa.sagepub.com/

Habbick, B. F., Nanson, J. L., Snyder, R. E., Casey, R. E., & Schulman, A. L. (1996). Foetal alcohol syndrome in saskatchewan: Unchanged incidence in a 20-year period. *Canadian Journal of Public Health/Revue Canadienne De Sante Publique, 87*(3), 204-207. Retrieved from http://journal.cpha.ca/index.php/cjph

Hammersley, M. (1987). Some notes on the terms 'validity' and 'reliability'. *British Educational Research Journal, 13*(1), 73-81.

Hanley, B., Tasse, M. J., Aman, M. G., & Pace, P. (1998). Psychometric properties of the family support scale with head start families. *Journal of Child and Family Studies, 7*(1), 69-77. doi:10.1023/A:1022912130180

Harrison, C., & Sofronoff, K. (2002). ADHD and parental psychological distress: Role of demographics, child behavioral characteristics, and parental cognitions. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(6), 703-711. doi:10.1097/00004583-200206000-00010

Haskett, M. E., Ahern, L. S., Ward, C. S., & Allaire, J. C. (2006). Factor structure and validity of the parenting stress index-short form. *Journal of Clinical Child & Adolescent Psychology, 35*(2), 302-312. doi:10.1207/s15374424jccp3502_14

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418. doi:10.1111/j.1365-2788.2005.00673.x

Hassall, R., & Rose, J. (2005). Parental cognitions and adaptation to the demands of caring for a child with an intellectual disability: A review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy, 33*(1), 71-88. doi:10.1017/S135246580400178X

Hautmann, C., Hoijtink, H., Eichelberger, I., Hanisch, C., Pluck, J., Walter, D., & Dopfner, M. (2009). One-year follow-up of a parent management training for children with externalizing behaviour problems in the real world. *Behavioural and Cognitive Psychotherapy, 37*(4), 379-396. doi:10.1017/S135246580999021X

Hellemans, K. G. C., Sliwowska, J. H., Verma, P., & Weinberg, J. (2010). Prenatal alcohol exposure: Fetal programming and later life vulnerability to stress, depression and anxiety disorders. *Neuroscience & Biobehavioral Reviews; Special Section: Developmental Determinants of Sensitivity and Resistance to Stress: A Tribute to Seymour "Gig" Levine, 34*(6), 791-807. doi:http://dx.doi.org/10.1016/j.neubiorev.2009.06.004

Hill, R. (1949). *Families under stress*. New York: Harper & Row.

Hill, R. (1958). Generic features of families under stress. *Social Casework, 39*, 139-150.

Hill, R. (1971). *Families under stress: Adjustment to the crises of war separation and reunion*. Westport, CT: Greenwood Press.

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family, 68*(4), 1069-1083. doi:10.1111/j.1741-3737.2006.00314.x

Howell, K. K., Lynch, M. E., Platzman, K. A., Smith, G. H., & Coles, C. D. (2006). Prenatal alcohol exposure and ability, academic achievement, and school functioning in adolescence: A longitudinal follow-up. *Journal of Pediatric Psychology, 31*(1), 116-126.

Huculak, S., & McLennan, J. D. (2009). *Service use and needs of families with children seen through FASD specialty clinics in alberta*. Calgary, AB: Alberta Centre for Child, Family and Community Research. Retrieved from http://www.research4children.com/

Ialongo, N. S., Werthamer, L., Kellam, S. G., Brown, C. H., Wang, S., & Lin, Y. (1999). Proximal impact of two first-grade preventive interventions on the early risk behaviors for later substance abuse, depression, and antisocial behavior. *American Journal of Community Psychology, 27*(5), 599-641. doi:10.1023/A:1022137920532

Institute of Health Economics. (2009). *Consensus statement on fetal alcohol spectrum disorder (FASD): Across the lifespan*. Edmonton, AB: Author. Retrieved from http://www.ihe.ca/documents/Consensus%20Development%20Conference%20on%20Fetal%20Alcohol%20Spectrum%20Disorder%20-%20Across%20the%20Lifespan.pdf

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health, 19*, 173-202.

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (2001). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health, 14*(- 2), 182-197.

Iverson, S. (2010). How to start and sustain a FASD support group. Paper presented at the *Paper Presentation at the 2010 Alberta FASD Conference,* Calgary, AB.

Jacobson, S. W., Jacobson, J. L., Sokol, R. I., Chiodo, L. M., & Corobana, R. (2004). Maternal age, alcohol abuse history, and quality of parenting as moderators of the effects of prenatal alcohol exposure on 7.5- year intellectual function. *Alcoholism: Clinical and Experimental Research, 28*, 1732-1745. doi:10.1097/01.ALC.0000145691.81233.FA

Jacobson, J. L., & Jacobson, S. W. (2002). Effects of prenatal alcohol exposure on child development. *Alcohol Research & Health, 26*(4), 282-286.

Jang, E. E., McDougall, D. E., Dawn, P., Herbert, M., & Russell, P. (2008). Integrative mixed methods data analytic strategies in research on school success in challenging circumstances. *Journal of Mixed Methods Research, 2*, 221-247. doi:10.1177/1558689808315323

Johnson, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology, 18*, 167-175. doi:10.1207/s15374424jccp1802_8

Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology, 18*(2), 167-175. doi:10.1207/s15374424jccp1802_8

Jones, K. L. (1999). The ecology of FAS/E: Developing an interdisciplinary approach to intervention with alcoholaffected children and their families. In J. Turpin, & G. Schmidt (Eds.), *Fetal alcohol syndrom effect: Developing a community response* (pp. 80-87). Halifax, NS: Fernwood.

Jones, K. L., & Smith, D. W. (1973). Recognition of the fetal alcohol syndrome in early infancy. *Lancet, 2*(7836), 999-1001. Retrieved from http://www.sciencedirect.com/science/journal/01406736

Jones, K. L., Smith, D. W., Ulleland, C. N., & Streissguth, A. P. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet, 1*, 1267-1271. Retrieved from http://www.sciencedirect.com/science/journal/01406736

Jones, T. L., & Prinz, R. J. (2005). Potential roles of parental self-efficacy in parent and child adjustment: A review. *Clinical Psychology Review, 25*(3), 341-363. doi:10.1016/j.cpr.2004.12.004

Kaminski, J. W., Valle, L. A., Filene, J. H., & Boyle, C. L. (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of Abnormal Child Psychology, 36*(4), 567-589. doi:10.1007/s10802-007-9201-9

Khanna, M. S., & Kendall, P. C. (2009). Exploring the role of parent training in the treatment of childhood anxiety. *Journal of Consulting and Clinical Psychology, 77*(5), 981-986. doi:10.1037/a0016920

Kodituwakku, P. W. (2009). Neurocognitive profile in children with fetal alcohol spectrum disorders. *Developmental Disabilities Research Reviews, 15*(3), 218-224. doi:10.1002/ddrr.73

Kodituwakku, P. W., Kalberg, W., & May, P. A. (2001). Effects of prenatal alcohol exposure on executive control functioning. *Alcohol Research and Health, 25*, 192-198.

Larsen, D. L., Attkisson, C. C., Hargreaves, W. A., & Nguyen, T. D. (1979). Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and Program Planning, 2*, 197-207.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer.

Lee, C., Hwang, F., Chen, C., & Chien, L. (2009). The interrelationships among parenting stress and quality of life of the caregiver and preschool child with very low birth weight. *Family & Community Health: The Journal of Health Promotion & Maintenance, 32*(3), 228-237. doi:10.1097/FCH.0b013e3181ab3b6a

Leech, N. L., & Onwuegbuzie, A. J. (2011). Beyond constant comparison qualitative data analysis: Using NVivo. *School Psychology Quarterly, 26*(1), 70-84. doi:10.1037/a0022711

Leenaars, L. S., Denys, K., Henneveld, D., & Rasmussen, C. (2012). The impact of fetal alcohol spectrum disorders on families: Evaluation of a family intervention program. *Community Mental Health Journal, 48*, 431-435. doi:10.1007/s10597-011-9425-6

Lemoine, P., Harrouseau, H., Borteyru, J. P., & Menuet, J. C. (1968). Les enfants de parents alcoholiques: Anomalies observees a propos de 127 cas. *Ouest Medical, 8*, 476-482.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Liu, C., Chao, Y., Huang, C., Wei, F., & Chien, L. (2010). Effectiveness of applying empowerment strategies when establishing a support group for parents of preterm infants. *Journal of Clinical Nursing, 19*(11-12), 1729-1737. doi:10.1111/j.1365-2702.2009.03082.x

Luck, L., Jackson, D., & Usher, K. (2006). Case study: A bridge across the paradigms. *Nursing Inquiry, 13*(2), 103-109. doi:10.1111/j.1440-1800.2006.00309.x

Manji, S., Pei, J., Loomes, C., & Rasmussen, C. (2009). A review of the verbal and visual memory impairments in children with foetal alcohol spectrum disorders. *Developmental Neurorehabilitation, 12*(4), 239-247. doi:10.1080/17518420902980118

Marcynyszyn, L. A., Maher, E. J., & Corwin, T. W. (2011). Getting with the (evidence-based) program: An evaluation of the incredible years parenting training program in child welfare. *Children and Youth Services Review, 33*(5), 747-757. doi:10.1016/j.childyouth.2010.11.021

Mash, E. J., & Johnston, C. (1983). Parental perceptions of child behavior problems, parenting self-esteem, and mothers' reported stress in younger and older hyperactive and normal children. *Journal of Consulting and Clinical Psychology, 51*(1), 86-99. doi:10.1037/0022-006X.51.1.86

Mash, E. J., & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology, 19*(4), 313-328. doi:10.1207/s15374424jccp1904_3

McAuley, C., McCurry, N., Knapp, M., Beecham, J., & Sleed, M. (2006). Young families under stress: Assessing maternal and child well-being using a mixed-methods approach. *Child & Family Social Work, 11*(1), 43-54. doi:10.1111/j.1365-2206.2006.00390.x

McBride, B. A. (1989). Stress and fathers' parental competence: Implications for family life and parent educators. *Family Relations: An Interdisciplinary Journal of Applied Family Studies, 38*(4), 385-389. doi:10.2307/585742

McCarty, C., Waterman, J., Burge, D., & Edelstein, S. B. (1999). Experiences, concerns, and service needs of families adopting children with prenatal substance exposure: Summary and recommendations. *Child Welfare, 78*(5), 561-577.

McCubbin, H. I., & McCubbin, M. A. (1991). Family stress theory and assessment: The resiliency model of family stress, adjustment, and adaption. In H. I. McCubbin, & A. I. Thompson (Eds.), *Family assessment inventories for research and practice* (pp. 3-32). Madison, WI: University of Wisconsin.

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage & Family Review, 6*(1-2), 7-37. doi:10.1300/J002v06n01_02

McCubbin, H. I., Thompson, A. I., Pirner, P. A., & McCubbin, M. A. (1988). *Family types and strengths: A life cycle and ecological perspective*. Minneapolis, MN: Burgess.

McIntyre, L. L. (2008). Parent training for young children with developmental disabilities: Randomized controlled trial. *American Journal on Mental Retardation, 113*(5), 356-368. doi:10.1352/2008.113:356-368

McLennan, J. D., Doig, J., Rasmussen, C., Hutcheon, E., & Urichuk, L. (2012). Stress and relief: Parents attending a respite program. *Journal of the Canadian Academy of Child & Adolescent Psychiatry, 21*(4), 261-269.

Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Miller, A. R. (2013). Diagnostic nomenclature for foetal alcohol spectrum disorders: The continuing challenge of causality. *Child: Care, Health & Development,* doi:10.1111/cch.12017

Minnes, P., Woodford, L., & Passey, J. (2007). Mediators of well-being in ageing family carers of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 20*(6), 539-552. doi:10.1111/j.1468-3148.2007.00364.x

Morawska, A., Winter, L., & Sanders, M. R. (2009). Parenting knowledge and its role in the prediction of dysfunctional parenting and disruptive child behaviour. *Child: Care, Health and Development, 35*(2), 217-226. doi:10.1111/j.1365-2214.2008.00929.x

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research
. *International Journal of Qualitative Methods, 1*(2), Article 2. Retrieved from http://www.ualberta.ca/~ijqm/

Mukherjee, R., Wray, E., Commers, M., Hollins, S., & Curfs, L. (2013). The impact of raising a child with FASD upon carers: Findings from a mixed methodology study in the UK. *Adoption & Fostering, 37*(1), 43-56. doi:10.1177/0308575913477331

National Institute for Health and Clinical Excellence. (2006). *Parent-training/education programmes in the management of children with conduct disorders*. London, UK: Author.

Niccols, A. (2008). 'Right from the start': Randomized trail comparing an attachment group intervention to supportive home visit. *Journal of Child Psychology and Psychiatry, 49*(7), 754-764. doi:10.1111/j.1469-7610.2008.01888.x

O'Connor, M., Shah, B., Whaley, S., Cronin, P., Gunderson, B., & Graham, J. (2002). Psychiatric illness in a clinical sample of children with prenatal alcohol exposure. *American Journal of Drug and Alcohol Abuse, 28*, 743-754.

O'Connor, M. J., Frankel, F., Paley, B., Schonfeld, A. M., Carpenter, E., Laugeson, E. A., & Marquardt, R. (2006). A controlled social skills training for children with fetal alcohol spectrum disorders. *Journal of Consulting and Clinical Psychology, 74*(4), 639-648. doi:10.1037/0022-006X.74.4.639

O'Connor, M. J., & Kasari, C. (2000). Prenatal alcohol exposure and depressive features in children. *Alcoholism: Clinical and Experimental Research, 24*(7), 1084-1092. doi:10.1111/j.1530-0277.2000.tb04654.x

O'Connor, M. J., Shah, B., Whaley, S., Cronin, P., Gunderson, B., & Graham, J. (2002). Psychiatric illness in a clinical sample of children with prenatal alcohol exposure. *The American Journal of Drug and Alcohol Abuse, 28*(4), 743-754. doi:10.1081/ADA-120015880

Oesterheld, J. R., Kofoed, L., Tervo, R., Fogas, B., Wilson, A., & Fiechtner, H. (1998). Effectiveness of methylphenidate in native american children with fetal alcohol syndrome and attention deficit/hyperactivity disorder: A controlled pilot study. *Journal of Child and Adolescent Psychopharmacology, 8*(1), 39-48. doi:10.1089/cap.1998.8.39

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, 32*(4), 251-261. doi:10.1037/h0087122

Olson, H. C., Feldman, J. J., Streissguth, A. P., Sampson, P. D., & Bookstein, F. L. (1998). Neuropsychological deficits in adolescents with fetal alcohol syndrome: Clinical findings. *Alcoholism: Clinical and Experimental Research, 22*(9), 1998-2012. doi:10.1097/00000374-199812000-00016

Olson, H. C., Jirikowic, T., Kartin, D., & Astley, S. J. (2007). Responding to the challenge of early intervention for fetal alcohol spectrum disorders. *Infants & Young Children, 20*(2), 172-189. doi:10.1097/01.IYC.0000264484.73688.4a

Olson, H. C., O'Connor, M. J., & Fitzgerald, H. E. (2001). Lessons learned from study of the developmental impact of parent alcohol use. *Infant Mental Health, 22*, 271-290. doi:10.1002/imhj.1001

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:10.1002/ddrr.65

Olson, H. C., Rudo-Stern, J., & Gendler, B. (2011). Supporting parents of children with fetal alcohol spectrum disorders, and young children with significant prenatal alcohol exposure. In M. O'Connor (Ed.), *Encyclopedia on early childhood development* (pp. 1-

10). Montreal, QC: Centre of Excellence for Early Childhood Development. Retrieved from http://www.child-encyclopedia.com/documents/Olson-Rudo-Stern-GendlerANGxp1.pdf.

Onwuegbuzie, A. J., Bustamante, R. M., & Nelson, J. A. (2010). Mixed research as a tool for developing quantitative instruments. *Journal of Mixed Methods Research, 4*, 56-78. doi:10.1177/1558689809355805

Onwuegbuzie, A. J., & Collins, K. M. (2007). A typology of mixed methods sampling designs in social science research. *The Qualitative Report, 12*, 281-316. Retrieved from http://www.nova.edu/ssss/QR/

Onwuegbuzie, A. J., & Johnson, R. B. (2006). The validity issue in mixed research. *Research in the Schools, 13*(1), 48-63. Retrieved from http://www.msera.org/rits.htm

Onwuegbuzie, A. J., & Leech, N. L. (2005). On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies. *International Journal of Social Research Methods, 8*, 375-387. doi:10.1080/13645570500402447

Onwuegbuzie, A. J., Leech, N. L., & Collins, K. M. T. (2011). Toward a new era for conducting mixed analysis: The role of quantitative dominant and qualitative dominant crossover mixed analysis. In M. Williams, & W. P. Vogt (Eds.), *The sage handbook of innovation in social research methods* (pp. 353-384). Thousand Oaks, CA: Sage.

Ostberg, M., & Hagekull, B. (2000). A structural modeling approach to the understanding of parenting stress. *Journal of Clinical Child Psychology, 29*(4), 615-625. doi:10.1207/S15374424JCCP2904_13

Padgett, L. S., Strickland, D., & Coles, C. D. (2006). Case study: Using a virtual reality computer game to teach fire safety skills to children diagnosed with fetal alcohol syndrome. *Journal of Pediatric Psychology, 31*(1), 65-70. doi:10.1093/jpepsy/jsj030

Paley, B., & O'Connor, M. J. (2009). Intervention for individuals with fetal alcohol spectrum disorders: Treatment approaches and case management. *Developmental Disabilities Research Reviews, 15*(3), 258-267. doi:10.1002/ddrr.67

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

Paley, B., O'Connor, M. J., Kogan, N., & Findlay, R. (2005). Prenatal alcohol exposure, child externalizing behavior, and maternal stress. *Parenting: Science and Practice, 5*(1), 29-56. doi:10.1207/s15327922par0501_2

Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., . . . Nelson, L. L. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research, 47*(4-5), 367-384. doi:10.1046/j.1365-2788.2003.00497.x

Patterson, J. M. (1988). Families experiencing stress: I. the family adjustment and adaptation response model: II. applying the FAAR model to health-related issues for intervention and research. *Family Systems Medicine, 6*(2), 202-237. doi:10.1037/h0089739

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Peadon, E., Rhys-Jones, B., Bower, C., & Elliott, E. (2009). Systematic review of interventions for children with fetal alcohol spectrum disorders. *BMC Pediatrics, 9*(35), 1-9. doi:10.1186/1471-2431-9-35

Pei, J., & Rinaldi, C. (2004). A review of the evolution of diagnostic practices for fetal alcohol spectrum disorder. *Developmental Disabilities Bulletin, 32*(2), 125-139.

Pisterman, S., Firestone, P., McGrath, P., Goodman, J. T., Webster, I., Mallory, R., & Coffin, B. (1992). The effects of parent training on parenting stress and sense of competence. *Canadian Journal of Behavioural Science, 24*(1), 41-58. doi:10.1037/h0078699

Plan:Net Limited, Strathcona Research Group, Coyne, K., & Cox, P.*A SMART fund guide to using outcomes to design & manage community health activities*. Vancouver, BC: SMART Fund.

Plano Clark, V. L., Garrett, A. L., & Leslie-Pelecky, D. L. (2010). Applying three strategies for integrating quantitative and qualitative databases in a mixed methods study of a nontraditional graduate education program. *Field Methods, 22*, 154-174. doi:10.1177/1525822X09357174

Plano Clark, V. L., Huddleston-Casas, C. A., Churchill, S. L., Green, D. O., & Garrett, A. L. (2008). Mixed methods approaches in family science research. *Journal of Family Issues, 29*(11), 1543-1566. doi:10.1177/0192513X08318251

Plant, K. M., & Sanders, M. R. (2007). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities, 28*(4), 362-385. doi:10.1016/j.ridd.2006.02.009

Plumb, M., Collins, N., Cordeiro, J. N., & Kavanaugh-Lynch, M. (2008).
Assessing process and outcomes: Evaluating community-based participatory research. *Progress in*

Community Health Partnerships: Research, Education, and Action, 2, 87-97. doi:10.1353/cpr.0.0020

Porty, S. (2009). *Non-biological caregivers' experiences of fetal alcohol spectrum disorder (FASD) support groups.* (Unpublished Master's). Wilfred Laurier University, Waterloo, ON.

Pottie, C. G., Cohen, J., & Ingram, K. M. (2009). Parenting a child with autism: Contextual factors associated with enhanced daily parental mood. *Journal of Pediatric Psychology, 34*(4), 419-429. doi:10.1093/jpepsy/jsn094

Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology, 22*(6), 855-864. doi:10.1037/a0013604

Powell, H., Mihalas, S., Onwuegbuzie, A. J., Suldo, S., & Daley, C. E. (2008). Mixed methods research in school psychology: A mixed methods investigation of trends in the literature. *Psychology in the Schools, 45*(4), 291-309. doi:10.1002/pits.20296

Premji, S., Serrett, K., Benzies, K., & Hayden, K. A. (2004). *The state of the evidence review: Interventions for children and youth with a fetal alcohol spectrum disorder (FASD).* . Edmonton, AB: Alberta Centre for Child, Family and Community Research. Retrieved from http://www.research4children.com/admin/docx/launch.cfm?ItemId=577

Raikes, H. A., & Thompson, R. A. (2005). Efficacy and social support as predictors of parenting stress among families in poverty. *Infant Mental Health Journal, 26*(3), 177-190. doi:10.1002/imhj.20044

Rasmussen, C. (2005). Executive functioning and working memory in fetal alcohol spectrum disorder. *Alcoholism: Clinical and Experimental Research, 29*(8), 1359-1367. doi:10.1097/01.alc.0000175040.91007.d0

Rasmussen, C., Horne, K., & Witol, A. (2006). Neurobehavioral functioning in children with fetal alcohol spectrum disorder. *Child Neuropsychology, 12*(6), 453-468. doi:10.1080/09297040600646854

Reitman, D., Currier, R. O., & Stickle, T. R. (2002). A critical evaluation of the parenting stress index-short form (PSI-SF) in a head start population. *Journal of Clinical Child & Adolescent Psychology, 31*(3), 384. doi:10.1207/S15374424JCCP3103_10

Riley, E. P., Mattson, S. N., Li, T. K., Jacobson, S. W., Coles, C. D., Kodituwakku, P. W., . . . Korkman, M. I. (2003). Neurobehavioral consequences of prenatal alcohol exposure: An international perspective. *Alcoholism: Clinical and Experimental Research, 27*(2), 362-373. doi:10.1097/01.ALC.0000052703.38558.B2

Robinson, G. C., Conry, J. L., & Conry, R. F. (1987). Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in british columbia. *Canadian Medical Association Journal, 137*, 203-207.

Roebuck-Spencer, T. M., & Mattson, S. N. (2004). Implicit strategy affects learning in children with heavy prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research, 28*(9), 1424-1431.

Rogers, H., & Matthews, J. (2004). The parenting sense of competence scale: Investigation of the factor structure, reliability, and validity for an australian sample. *Australian Psychologist, 39*(1), 88-96. doi:10.1080/00050060410001660380

Ryan, D. M., Bonnett, D. M., & Gass, C. B. (2006). Sobering thoughts: Town hall meetings on fetal alcohol spectrum disorders. *American Journal of Public Health, 96*(12), 2098-2101. doi:10.2105/AJPH.2005.062729

Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model. *Journal of Intellectual Disability Research, 47*(4-5), 300-312. doi:10.1046/j.1365-2788.2003.00492.x

Sanders, J. L. (2008). *Biological and non-biological parents' experiences raising children with FASD.* (Unpublished Master's). University of Alberta, Edmonton, AB.

Santos, F. M., & Eisenhardt, K. M. (2004). Multiple case study. In *The SAGE Encyclopedia of Social Science Research Methods.* M. S. Lewis-Beck, A. Bryman, & T. F. Liao (Eds). Thousand Oaks, CA: SAGE.

Scheel, M. J., & Rieckmann, T. (1998). An empirically derived description of self-efficacy and empowerment for parents of children identified as psychologically disordered. *American Journal of Family Therapy, 26*(1), 15-27. doi:10.1080/01926189808251083

Schoeder, C. E., & Remer, R. (2007). Perceived social support and caregiver strain in caregivers of children with tourette's disorder. *Journal of Child and Family Studies, 16*(6), 888-901. doi:10.1007/s10826-007-9133-6

Sepa, A., Frodi, A., & Ludvigsson, J. (2004). Psychosocial correlates of parenting stress, lack of support and lack of confidence/security. *Scandinavian Journal of Psychology, 45*(2), 169-179. doi:10.1111/j.1467-9450.2004.00392.x

Sgarbossa, D., & Ford-Gilboe, M. (2004). Mother's friendship quality, parental support, quality of life, and family health work in families led by adolescent mothers with preschool children. *Journal of Family Nursing, 10*(2), 232-261. doi:10.1177/1074840704263989

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

Shriver, M. D., & Allen, K. D. (2010). Parent training: Working with families to develop and implement interventions. In G. Gimpel Peacock (Ed.), *Practical handbook of school psychology: Effective practices for the 21st century* (pp. 408-421). New York, NY: Guilford Press.

Shriver, M. D., & Allen, K. D. (2008). *Working with parents of noncompliant children: A guide to evidence-based parent training for practitioners and students* (1st ed.). Washington, DC: American Psychological Association.

Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 111*, 155-169. Retrieved from http://www.aaiddjournals.org/loi/ajmr.1

Singer, G. H. S., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation & Developmental Disabilities Research Reviews, 13*(4), 357-369. doi:10.1002/mrdd.20175

Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry, 71*(2), 257-261.

Snyder, J., Nanson, J. L., Snyder, R., & Block, G. W. (1997). A study of stimulant medication in children with FAS. In Streissguth A.P., & Kanter J. (Eds.), *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities* (pp. 64-77). Seattle, WA: University of Washington Press.

Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology, 29*(1), 113-132. doi:10.1023/A:1005253514140

Square, D. (1997). Fetal alcohol syndrome epidemic on manitoba reserve. *Canadian Medical Association Journal, 157*(1), 59-60. Retrieved from http://www.cmaj.ca/

Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., . . . Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost
 . *Canadian Journal of Clinical Pharmacology, 16*, e91-e102.

Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: Sage.

Stake, R. E. (2005). Qualitative case studies. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The sage handbook of qualitative research* (3rd ed., pp. 443-466). Thousand Oaks, CA: Sage.

Stake, R. E. (2006). *Multiple case study analysis*. New York, NY: The Guilford Press.

Stake, R. E., & Trumbull, D. J. (1982). Naturalistic generalizations. *Review Journal of Philosophy & Social Science, 7*(1 & 2), 1-12.

Streissguth, A. P. (2001). Recent advances in fetal alcohol syndrome and alcohol use in pregnancy. In D. P. Agarwal, & H. K. Seitz (Eds.), *Alcohol in health and disease* (pp. 303-324). New York, NY: M. Dekker.

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. P., Randels, S. P., & Smith, D. F. (1991). A test-retest study of intelligence in patients with fetal alcohol syndrome: Implications for care. *Journal of the American Academy of Child & Adolescent Psychiatry, 30*(4), 584-587. doi:10.1097/00004583-199107000-00009

Tashakorri, A., & Creswell, J. W. (2007). Editorial: The new era of mixed methods. *Journal of Mixed Methods Research, 1*, 3-7. doi:10.1177/2345678906293042

Teddlie, C., & Tashakorri, A. (2003). Major issues and controversies in the use of mixed methods n the social and behavioral sciences. In A. Tashakorri, & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 3-50). Thousand Oaks, CA: Sage.

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual & Developmental Disability, 29*(1), 16-26. doi:10.1080/13668250410001662892

Tsui, L., Chapman, S. A., Schnirer, L., & Stewart, S. (2006). *A handbook on knowledge sharing: Strategies and recommendations for researchers, policymakers, and service providers*. Edmonton, AB: Community-University Partnership for Children, Youth, and Families. Retrieved from http://www.cup.ualberta.ca/wp-content/uploads/2011/06/Knowledge_Sharing_Handbook.pdf

Turner, L. A., & Johnson, B. (2010). Stress and coping in families of children with disabilities: A mixed research perspective. In K. M. T. Collins, A. J. Onwuegbuzie & Q. Jiao (Eds.), *Toward a broader understanding of stress and coping: Mixed methods approaches* (pp. 147-167). Charlotte, NC: Information Age.

Victor, C. R., Ross, F., & Axford, J. (2004). Capturing lay perspectives in a randomized control trial of a health promotion intervention for people with osteoarthritis of the knee. *Journal of Evaluation in Clinical Practice, 10*(1), 63-70. doi:10.1111/j.1365-2753.2003.00395.x

Walls, L. J., & Pei, J. (2013). FASD service delivery: Exploring current systems of care from the caregivers' perspective. *The International Journal of Alcohol and Drug Research; Early View Papers and Abstracts,*

Warren, K., Floyd, L., Calhoun, F., Stone, D., Bertrand, J., Streissguth, A., . . . Litle, A. (2004). *Consensus statement on FASD: Across the lifespan*. Washington, DC: National Organization on Fetal Alcohol Syndrome (NOFAS). Retrieved from www.ihe.ca/documents/FinalWeb_FASDStatement.pdf

Watson, S. L., Coons, K. D., & Hayes, S. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. part I: A comparison of parenting stress. *Journal of Intellectual and Developmental Disability, 38*(2), 95-104. doi:10.3109/13668250.2013.788136

Watson, S. L., Hayes, S., 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 and Developmental Disability, 38*(2), 105-113. doi:10.3109/13668250.2013.788137

Watson, S. L., & Radford-Paz, E. (2010). *"It's like being on a rollercoaster": Resiliencies and challenges of raising a child with FASD in northern ontario*
. 2010 Northern Health Conference, Sudbury, ON.

Webster-Stratton, C. (1990). Stress: A potential disruptor of parent perceptions and family interactions. *Journal of Clinical Child Psychology, 19*(4), 302-312. doi:10.1207/s15374424jccp1904_2

Webster-Stratton, C. (1992). *The incredible years: A trouble-shooting guide for parents of children aged 3-8*. Toronto, ON: Umbrella Press.

Webster-Stratton, C., & Herman, K. C. (2010). Disseminating incredible years series early-intervention programs: Integrating and sustaining services between school and home. *Psychology in the Schools, 47*(1), 36-54. doi:10.1002/pits.20450

Webster-Stratton, C., & Reid, M. J. (2003). The incredible years parents, teachers, and child training series: A multifaced treatment approach for young children with conduct problems. In A. E. Kazdin, & J. R. Weisz (Eds.), *Evidence-based psychotherapies for children and adolescents* (pp. 224-240). New York, NY: Guilford Press.

Webster-Stratton, C., Reid, M. J., & Hammond, M. (2004). Treating children with early-onset conduct problems: Intervention outcomes for parent, child, and teacher training. *Journal of Clinical Child and Adolescent Psychology, 33*(1), 105-124. doi:10.1207/S15374424JCCP3301_11

Weinberg, J., Sliwowska, J. H., Lan, N., & Hellemans, K. G. C. (2008). Prenatal alcohol exposure: Foetal programming, the hypothalamic-pituitary-adrenal axis and sex differences in outcome. *Journal of Neuroendocrinology, 20*(4), 470-488. doi:10.1111/j.1365-2826.2008.01669.x

Wheeler, A. C., Skinner, D. G., & Bailey, D. B. (2008). Perceived quality of life in mothers of children with fragile X syndrome. *American Journal on Mental Retardation, 113*(3), 159-177. Retrieved from Retrieved from http://www.aaiddjournals.org/loi/ajmr.1

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

Williams, R. J., Odaibo, F. S., & McGee, J. M. (1999). Incidence of fetal alcohol syndrome in northeastern manitoba. *Canadian Journal of Public Health, 90*, 192-194. Retrieved from http://journal.cpha.ca/index.php/cjph

Wilton, G., & Plane, M. B. (2006). The family empowerment network: A service model to address the needs of children and families affected by fetal alcohol spectrum disorders. *Pediatric Nursing, 32*(4), 299-306. Retrieved from http://www.pediatricnursing.net/

Wood-Dauphinee, S. (1999). Assessing quality of life in clinical research: From where have we come and where are we going?
. *Journal of Clinical Epidemiology, 52*(4), 355-363. Retrieved from http://www.jclinepi.com/

Yalom, I. D., & Leszcz, M. (2005). *The theory and practice of group psychotherapy* (5th ed.). New York, NY: Basic Books.

Yin, R. K. (2006). Mixed methods research: Are the methods genuinely integrated or merely parallel? *Research in the Schools, 13*(1), 41-47. Retrieved from http://www.msera.org/rits.htm

Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). Los Angeles, CA: Sage.

Yin, R. K. (2010). *Qualitative research from start to finish
*. New York, NY: Guilford Press.

Zelazo, P. D., & Muller, U. (2002). Executive function in typical and atypical development. In U. Goswami (Ed.), *Blackwell handbook of childhood cognitive development* (pp. 445-469). Malden: Blackwell Publishing. doi:10.1002/9780470996652.ch20

Appendix A: The Community-Based Research and Evaluation (CBRE) Context

The CBRE Context

CBRE arose from other participatory research approaches, including participatory action research and action research, which have similar but slightly different modes of implementation. The Centre for Community-Based Research in Kitchener, Ontario (n.d.), has defined CBRE as three fold: (a) research that strives to be situated in the community by investigating a topic that is relevant to the community, (b) with community members and researchers working collaboratively in the designing and implementing the research, and that (c) focuses on the usefulness of the process and results to facilitate social change. Furthermore, in a seminal work on CBRE, Israel, Schluz, Parker, and Becker (1998) outlined several important principals of CBRE that can be incorporated into the research process. These principles include, but are not limited to: (a) recognizing the community as a unit of identity; (b) building on the strengths and resources of the community; (c) facilitating collaborative partnerships in all phases of the research process; (d) integrating knowledge and action for benefit of all partners; (e) promoting co-learning and empowerment; (f) involving cyclical and iterative processes; (g) approaching health from a positive and ecological view; (h) sharing knowledge to all involved partners (see Israel et al., 1998p. 178-180). Like all research, each of these principles of CBRE can be situated on a continuum. Although not all principles will be heavily endorsed in all CBRE studies, each of the principles should be at least partially reflected. The process of CBRE provides opportunities for research to be conducted with communities on issues that are relevant and valued by community stakeholders.

Previous research on interventions for individuals with FASD has emphasized that CBRE will play a critical role in helping communities create positive change (ACCFCR, 2010). In order to learn more about this approach and to better understand how to best serve community-based organizations using a CBRE approach, the primary research obtained the Embedded Graduate Certificate in CBRE, through the Community-University Partnership for the Study of Children, Youth, and Families (CUP) at the University of Alberta. Knowledge gained from this program helped to inform the current research study. The project also served as an opportunity for the primary investigator to learn about CBRE. The current research project was used as a Supervised CBRE Experience, which provided an opportunity to develop methodological and conceptual competencies in CBRE, and was a requirement of the Embedded Graduate Certificate in CBRE. As part of the certificate program, Sharon Schultz (Program Supervisor of Coaching Families and Step by Step Programs) served as a community mentor for this project, with support from Denise Plesuk (current Program Manager of Catholic Social Services FASD programs). Community mentors help students in many areas related to CBR, including helping the student with community issues, providing the student with information related to the community context, and mentoring the student in partnership work. Dr. Christina Rinaldi acted as my graduate supervisor/academic mentor. See below for more information regarding the learning objectives of the CBRE Experience project and how they were evaluated.

As a CBRE project, the current research study employed collaboration among community, used a shared research and evaluation agenda, and demonstrated the principles and philosophy of CBRE. The research project was designed in collaboration with Coaching Families, a program run through Catholic Social Services aimed at providing support, advocacy, education, and referrals to caregivers of children with FASD. Members of the Coaching Families program have attempted to start a well-attended support group for caregivers of children with FASD in the Edmonton area for several years, but without much success. However, in the last year, Denise Davis, a mentor with Coaching Families, has found pairing support group meetings with educational or information sessions has helped to increase caregiver attendance and involvement. Denise Davis was consulted regarding the needs of primary caregivers of children with FASD and the current project, along with the following individuals: Dorothy Henneveld, former Program Manager for Catholic Social Services FASD programs; Denise Plesuk, current Program Manager of Catholic Social Services FASD programs; Sharon Schultz, Program Supervisor of Coaching Families and Step by Step Programs; the Coaching Families team; and Gerry Wright, former Project Lead, Government of Alberta FASD 10-Year Strategic Plan.

The original proposed program, designed in collaboration with Coaching Families, consisted of a educational components that were more structured and placed a larger emphasis on information regarding FASD than connecting participants to services in the community (see below). The original proposal planned eight 90-minute biweekly sessions. However, through the CBRE process it was determined, due to time constraints, participant input, and the community-based focus of the project (described below), the intervention consisted of five three-hour monthly sessions that included a range of both psychoeducational (i.e., providing information and reframing ideas of parenthood) and support (i.e., discussions of difficulties with other caregivers in a supportive environment) components at each session. Instead, focus was given to an evaluation of the current psychoeducational support group held by Coaching Families in its current form, as that would be more appropriate for the needs of research members. The program could be conceptualized as a preventative measure for helping caregivers deal with the stress and struggles of raising a child with FASD. Through consultations, the aspiration, appropriateness, and feasibility for conducting research associated with the implementation an educational workshop and support group for caregivers was established. As with many CBRE projects, the design of the program was an iterative process that changed over time, which works well with the flexibility of the case study approach. Coaching families also assisted with recruitment of participants and the implementation of various psychoeducational and support aspects of the intervention. Caregivers were consulted regarding the research study and provided input regarding the research study when possible, although overall few members chose to do. Member checking with participants was also conducted, although few participants chose to do so. Data analysis and integration of the mixed methods information was done in consultation with the Coaching Families team. A flyer was later created, based on information from the study, to recruit new caregivers to the intervention, which is shown below.

The current project fits with the principles and philosophy of CBRE. Israel, Schluz, Parker, and Becker (1998; 2001) have outlined nine principals of CBRE. Four of these principles are reflected in the following ways. First, the scope of the project remained manageable and appropriate to the resources available to Coaching Families in order to build on the strengths and resources of the community. Additionally, the completion of research activities was based on the strengths of members; I have expertise in applying for ethics and helped draft the ethics application, whereas Coaching Families members were invaluable in helping to analyze interview information. Second, since inception, collaborative partnerships have been promoted through discussions with research members during each phase of the project. Research has suggested that using a collaborative framework for research may help to improve methodology and benefits communities (Plumb, Collins, Cordeiro, & Kavanaugh-Lynch, 2008). Third, the purpose of the study was to inform services for caregivers. Therefore, it is hoped the results benefited all members. It is the intent of the research project that the information will help to provide caregivers with improved services, service providers will learn how to improve their services, and the primary investigator gained additional CBRE experience while learning about services for caregivers of children with FASD. Fourth, all members were provided with the opportunity to participate in knowledge sharing (KS) activities about the results of the project. Overall, the level of partnership of the current CBRE project could be categorized as a cooperative relationship, where parties plan together and share some responsibilities. See below for a final draft of the KS plan.

Throughout the CBRE Experience, I saw my role in the study as being that of a project facilitator. As a project facilitator and doctoral student, I lead many of the research activities and promoted consultation and collaboration with research members through open discussion and exchange. In this role, I helped to organize meetings, drafted the ethics application, and facilitated discussions concerning various elements of the project, including the research questions, interview questions, questionnaire selection, analyses, and knowledge sharing plan. Involvement in these activities by research members and participants was based on the desires and time commitments of each member.

Due to the nature of this dissertation research project, the current study did not take a purely participatory approach to CBRE. However, decisions regarding the research project were made in collaboration between the researcher and the Coaching Families team as much as possible through ongoing discussions, including discussions concerning the research questions, interview questions, questionnaire selection, analyses, and KS plan.

As part of the collaboration, the research members constructed a KS plan to be implemented after the completion of the project (see below). KS is defined as "the process of exchanging knowledge (skills, experience, and understanding) among researchers, policymakers, and service providers" (Tsui, Chapman, Schnirer, & Stewart, 2006, p. 5) and is an important component to CBRE. The findings of the psychoeducational support group were shared with the Coaching Families team and caregivers through a handout of preliminary findings (see below) and a short executive summary. A flyer for the support group was also made using some quotes from the participants (see below). Findings from this research will also be communicated through selected conferences (e.g., International FASD conference, Alberta FASD conference), peer-reviewed journal articles, and FASD newsletters or networks (e.g., FASD Frontline Newsletter). Additional KS activities may be employed as the researchers or community mentors’ awareness of suitable activities increases. It is hoped knowledge gained from the research project will help to identify what aspects of the intervention were helpful and impactful for caregivers in order to help inform the Coaching Families team regarding their programming for caregivers of children with FASD.

Edwards, Lund, and Gibson (2008) suggested *ethical validity* in CBRE research is achieved when all aspects of the research process are consistent with the ethical principles of all research partners. As such, ethical principles of all the research members, including members of the Coaching Families team and myself, were discussed throughout the course of the project. Several steps were taken to enhance the *ethical validity* of the study. The study was reviewed for its adherence to the ethical guidelines and approved by the Research Ethics Board at the University of Alberta. The researcher signed an oath of confidentiality for the purposes of working with *Coaching Families* and attending support group meetings. Informed consent was obtained from each participant involved in the project. Pseudonyms were used whenever discussing data collection and results. Confidentiality was ensured as much as possible in the context of the group intervention.

The following is a letter addressed to the CBRE Certificate Coordinator that provides additional details regarding my experience. It includes a table outlining the learning goals for my CBRE Experience and how my community mentor, graduate supervisor/university mentor (Dr. Christina Rinaldi), CBRE Certificate Coordinator (Dr. Sherry-Ann Chapman), and myself evaluated how I responded to these goals. The letter is followed by the originally proposed intervention, the final KS plan created with research members, an overview of the challenges of completing a CBRE project, as well as flyer created for the program to recruit new caregivers for participation. The flyer includes information gathered through the current research project and is one example of a knowledge sharing activity created as part of the CBRE process.

The CBRE Experience

September 30, 2012

Re: CBRE End-of-Experience Letter

Dear Dr. Sherry Ann Chapman,

I am writing you an end-of-experience letter as my experience slowly comes to a close. In order to provide you with some information regarding my experience, I have attempted to answer the guiding questions regarding my learning experiences and knowledge-sharing plan:

(a) How would you describe the second half of your CBRE Experience, after the midway check-in?

The second half of my CBRE experience, after the midway check-in, has been a wonderful experience. I have really appreciated the time and support my community mentors have given me throughout the past few months as the project is being wrapped up and we're able to discuss the results of the project as they evolve. I have enjoyed getting to know the research team over the course of the experience. Unfortunately, the second half of the CBRE experiences was fairly rushed as I prepared to move to Guelph, ON. Since the middle of August the research team is communicating primarily through email as we discuss some of the results of the project and create a presentation for the Alberta FASD conference. It is my hope that the research team can continue to communicate openly as we work long distance. In the future, in participating CBRE projects, I hope to create more realistic timelines.

(b) Please describe how you have responded to each of your personal learning objectives.

I have responded to each of my personal learning objectives in the following ways:

	Learning Objective	Evaluation	Response
1.	Increase my **knowledge** of how to develop collaborative relationships and how to maintain those relationships	Log of activities of working collaboratively and keep a reflective journal of my experiences. The logs and journal can be shared with my community mentor over coffee at the end of the project.	The log of activities working collaboratively was shared with my community mentor, Sharon Schultz, and her supervisor, Denise Plesuk, on July 26 at the Coaching Families offices. I spoke with them about my experiences, what I learned through the process, the importance of keeping a reflective journal, and what I would

			have done differently.
2.	Participate in the development of a **knowledge sharing plan**	In collaboration with the research team, create a knowledge sharing plan. The creation of the plan and implementation of a part of the plan (to be determined) will be an indicator that the learning objective has been achieved.	In collaboration with the research team, a knowledge sharing plan was created. Part of the plan has been implemented. See below regarding specific information of what has been completed. In particular, we have completed the CUP poster, BBQ and newsletter, Coaching Families staff meeting, and brochure. Member checking and follow up is being completed on a ongoing basis. The Alberta FASD conference presentation will be completed in October and the International FASD poster presentation will take place in February. It has hoped that this information can be helpful for other community groups working with caregivers of children with FASD.
3.	Implement a small element of a **process evaluation** of the partnership	Receive feedback from some of the research members (with the exception of Dr. Pei and Dr. Poth) regarding how the partnership is progressing at least three times during the partnership. The execution of the process evaluation will be evidence that the learning objective has been achieved.	Feedback was solicited from some of the research members (Christina Rinaldi, Sharon Schultz, and Denise Plesuk) on May 1 and July 26, and will be solicited again after the end of September.

(c) What is one particular moment of learning that occurred outside of your personal learning objectives? For example, did unanticipated insights develop for you regarding CBRE? Did anything surprise you in light of expectations that you may have had prior to starting your Experience?

There was not any particular, unanticipated moment in learning that occurred during the experience. However, I feel I began to understand the general principles of CBRE and why this particular approach can be effective and empowering. I began to understanding how open, interested, and involved community members are when they care about the project and are given the opportunity to be involved in the project, not only as a participant but as co-creators of the project. Of course, learning about the theory of CBRE I knew this could be the case, but it was interesting to learn this through experience.

(d) What challenges did you face in your CBRE Experience? What did they add to your learning about the real-life application of CBRE? Was there anything in particular that you found 'easier in theory than in practice'?

I encountered several challenges when completing my CBRE experience. The first challenge was the timing of the project. Because of the timing of the intervention and the beginning of my internship, the planning for the project became very tricky and restricted. Unfortunately, the number of times we could collect data was reduced because of the last start of the project (partly because of the time it took to build relationships and complete our ethics application). And due to my move to Guelph, ON, we did not have the time that I would have liked to spend analyzing the data with community members. We may have missed opportunities for some capacity building, although community members never expressed those particular wishes. We spent time building relationships and it felt rushed and cut short when I left. I feel we could have done more and I am regretful that I had to leave when we did. I felt I had just begun to understand the theory and mechanisms of CBRE projects and then had to leave to begin my internship. In the future I hope to be involved with CBRE projects for a longer time period as needed.

(e) What opportunities arose during your CBRE Experience?

Except to be involved with the support group intervention that was a part of the data collection process for the project, no other specific opportunities arose during my CBRE experience. However, I would like to use the skills have I have learned through this experience with other CBRE projects, possibly with the

(f) What insights from your mentoring relationships have been most helpful or pivotal for you? Why?

I believe my mentors' enthusiasm, understanding, and support were the most important and helpful to me as the project progressed. This was the first time I was involved in a CBRE experience and it was helpful to know they did not expect me to be the CBRE expert. My community mentors and I learned about CBRE as we went, and it was helpful to know that we were all there to support one another.

(g) If you were to identify one word or phrase to describe your hands-on experience in CBRE, what would that word or phrase be?

I see my CBRE experience as the beginning of a lifelong learning endeavor. I would like to be involved with other CBRE projects, as possible, to further understand how this particular methodology can be used. I am interested to see how this could be used within school districts to address issues that are important to teachers and parents.

(h) Finally, please share your thoughts on the knowledge-sharing plan for your CBRE Experience. Which knowledge-sharing activities have been completed at this point? Have there been any immediate outcomes? What do you foresee as the potential impact of these knowledge-sharing activities?

In collaboration with the research team, a knowledge-sharing plan was created. Part of the plan has been implemented. In particular, so far we have completed the CUP poster, BBQ and newsletter, Coaching Families staff meeting, and brochure. It was different experience for me to sit down as a team and decide before hand and throughout the project how any information would be disseminated and why. Prior to this experience, knowledge-sharing activities were based on the availability to attend conferences and create journal submissions. It was a learning opportunity for me to share verbally some of the results (what has been completed so far) with the participants in the project in relevant manner. It was insightful to have a conversation with them about the results of the project and to hear their reactions. Member checking and follow up is being completed on an ongoing basis. The Alberta FASD conference presentation will be completed in October and the International FASD poster presentation will take place in February. It has hoped that this information can be helpful for other community groups working with caregivers of children with FASD.

Thank you again for all your help. If you have additional questions or comments, please do not hesitate to contact me at kroger@ualberta.ca.

Sincerely,
Katherine Roger

Overview of the Originally Proposed Group

Content description:

Component 1: Understanding your child with FASD

- Introductions
- Review goals
- Review rules
- Introduction to FASD
- Deliver in workshop/discussion/film format
- Basic review of etiology (i.e. Wiring in a House metaphor)
- Review of neurocognitive deficits (brain impairment)
- Distinguishing Primary and Secondary deficits
- Will use existing resources (i.e. from Region 6; Lakeland Centre, etc.)
- How does FASD impact your child?
- Review of Intro to FASD followed by open group discussion
- Parents encouraged to share anecdotes regarding their child's gifts and challenges

Component 2: Strategies

- How does FASD impact how you parent?
- Deliver in workshop/discussion/film format
- Review of FASD parenting strategies with reference to neurocognitive deficits (brain impairment) using Region 6 - Strategies, Not Solutions or other handbook
- Do not discourage from trying other acceptable strategies
- Being the external brain (Jiminy Cricket filmstrips)
- Set realistic expectations (re-define success)
- Strength-based, individualized approach
- Consistency, not perfection

Component 3: Understanding your role as a parent

- How does FASD impact who you are as a parent?
- Workshop/group discussion format
- Extended caregiver roles (greater child needs)
- Other roles:
  - Advocate
  - Peer support
  - You may be the expert among experts; many professionals lack knowledge of FASD
  - Potential is there for the need to be a "lifelong parent"
- Promoting an optimistic but realistic autonomy

Component 4: How does raising a child with FASD impact your life?

- Guided group discussion format

- Birth and non-birth parents often feel:
    - Grief and loss
    - Shame and guilt
- Parents of children with FASD tend to experience greater stress, especially knowing that the disorder is preventable
- Self-care (why and how)
- Many non-birth parents feel anger and resentment
- Many birth parents feel regret and depression
- Resources

Intervention components are based on information gathered from several organizations in Western Canada including Coaching Families*, a* Catholic Social Services *program in Edmonton, the Saskatchewan FASD Network, and the Parent Support Association of Calgary* (see Iverson, 2010 regarding support groups in Calgary, AB). *Information was also gathered from the* Practical Handbook for School Psychology (Briesmeister & Schaefer, 2007)*, the* Handbook of Parenting Training (Shriver & Allen, 2010)*, and additional resources on parent intervention groups* (Dishion, 2007)*.*

Knowledge Sharing Plan

FINAL (Updated: September 28, 2014)

The following knowledge sharing (KS) plan is based on the suggested categories provided in the Knowledge Transition and Transfer plan template developed by the Ontario Ministry of Agriculture, Food and Rural Affairs (June, 2010). This KS plan was created in collaboration with Denise Plesuk, Sharon Schultz, and Christina Rinaldi.

	KS Activities	*Target Audience(s)/ User Groups*	*Proposed Timeline*	*Individuals Involved in KS*	*Intended Benefits of KS Activities*
1.	*CUP poster (completed, won the Most Engaging Poster Award)*	Researchers, community members	Poster session held on May 23, 2012.	Katherine, Christina, Denise P., and Sharon help to create the poster and interactive activities. Katherine, Denise P., and Sharon attended the poster session.	Focus on the research design overview (no results ready): To provide information to the larger community of researchers and practioners regarding the research project, Catholic Social Services FASD programs, and FASD.
2.	*Member checking and follow up*	Support group research project participants	Complete by the 4th week in July (after the interviews have been transcribed and coding has started) – July 23 to July 27, 2012.	Katherine and participants	Support group research participants get to hear more information about the project and have input into the final results and outcome of the project.
3.	*BBQ lunch and newsletter*	Support group members	• Held on Wednesday, August 8, 2012 from 11:30-1 at the Jasper Ave. Complex (JAC) building/Coaching Families offices • Brought CUP	Katherine, Coaching Families staff (Denise D., Denise P., and Sharon), and support group members.	Support group members (both those that participated and those that did not) get to hear an overview of the results.

			poster as well so caregivers can see it.		
4.	*Meeting*	Coaching Families staff	Completed the same day of the BBQ	Katherine and Coaching Families staff	Coaching Families staff gets to hear an overview of the results and learn how the research project turned out.
5.	*Brochure*	Future support group members, Coaching Families participants	Send to Denise P., Sharon, and Denise D. by the 4th week of August (by August 30, 2012) for distribution in September.	Katherine will draft a copy and then have Denise P., Sharon, and Denise D. provide feedback.	To provide caregivers with information regarding the support group and what caregivers have gotten out of the group (in general) in order to promote it in this coming year.
6.	*Alberta FASD conference in Edmonton presentation (Accepted 2012 & 2014)*	Researchers, practitioners	- Submitted abstract May 31, 2012. - Accepted for 20 minute presentation and 5 minutes for questions - Completed: *October 23, 2012,9:15-10:30* & *October 20, 2014, 9:30-10:30*	Katherine, Christina, Denise P., and Sharon will help to create the presentation. Denise and Sharon will present the information.	Focus on the support group, "qualitative", and "evaluation" aspect: To present information on the study and results to members of the FASD community (researchers and practioners) in Alberta.
7.	*International FASD conference in Vancouver poster (Accepted, 2013 & 2015)*	*Researchers, practitioners*	- *Submitted abstract May 31.* - *Submission included:* ○ *75 word biography outlining our FASD experience;* ○ *500 word max presentation summary* ○ *2-4 learning*	*Katherine, Christina, Denise P., and Sharon will help to create the poster and interactive activities. Katherine will attend the poster session, and Denise P.*	*Focus on "evaluation" aspect (overall): To provide information regarding mixed methodology and community-based research, as well as the results of the study, to researchers and practioners in the field of FASD.*

			objectives - *Conference: February 27 to March 2, 2013, and March 4-7, 2015 in Vancouver*	*and/or Sharon will attend the conference, and Katherine will join them if possible.*	
8.	*Possibly CPA poster (if time allows and accepted)*	*Researchers, practioners*	- *Deadline for abstracts is typically November 1.* - *Send abstract draft by September 30*	*Katherine, Christina, Denise P., and Sharon will help to create the poster and interactive activities. Katherine will attend the poster session.*	*Focus on the "mixed methods" aspect: To provide information regarding mixed methodology in a community psychology project, as well as provide information regarding FASD.*
9.	*Possibly Community Mental Health Journal or other journal (if accepted)*	*Researchers, practitioners*	- *TBA* - *Once more of the dissertation is written we will have a better understanding of what journal may be appropriate.*	*To be a collaborative effort of the research team (Katherine, Christina, Jacquie, Cheryl, Denise P., and Sharon), led by Katherine.*	*Overall picture: To provide information regarding the study and results to the larger community.*
10.	*Possibly Mixed Methods International Research Association Inaugural Conference (if accepted)*	*Researchers, practitioners*	- *Deadline for paper submissions is TBA* - *Conference will be held at Boston College, Boston, June 27-29, 2014*	*To be a collaborative effort of the research team (Katherine, Christina, Jacquie, Cheryl, Denise P., and Sharon), led by Katherine.*	*Overall picture: To provide information regarding the mixed methods used for completion of the study in order to share them with the larger mixed methods community.*

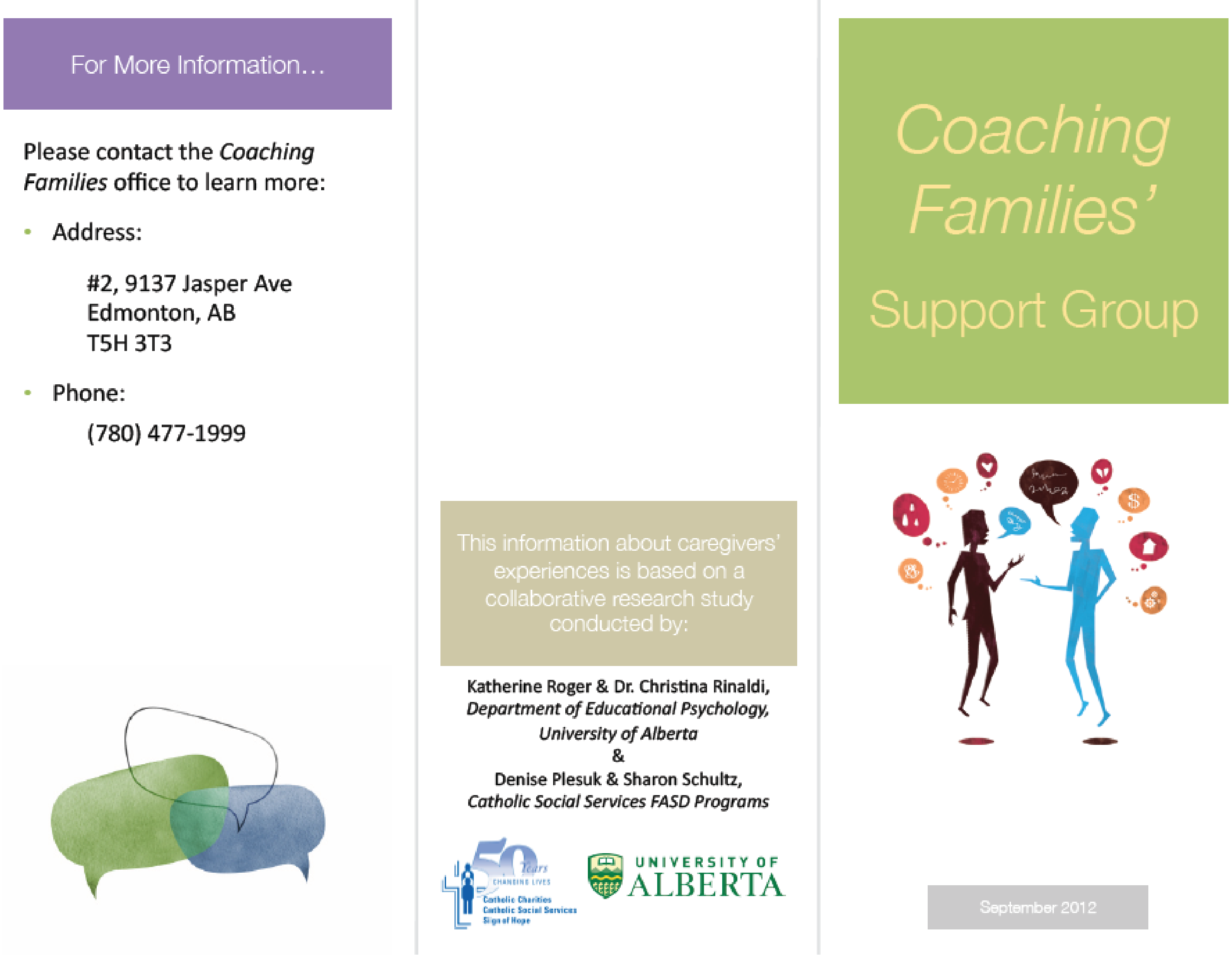
Challenges of Using CBRE

Several challenges arose during the process relating to the implementation of a mixed methods study in a CBRE process: (a) time, (b) understanding and clarity of roles, and (c) lack of expertise.

First, like many other CBRE projects, using a mixed methods approach within a CBRE context was a time-consuming process, which as been previously addressed by several researchers, both within the context of CBRE (e.g., Flicker, Savan, McGrath, Kolenda, & Mildenberger, 2008; Israel, Schulz, Parker, & Becker, 1998) and mixed methods research (Creswell & Plano Clark, 2011). Due to the iterative process of CBRE, it was wished that there was more time to develop and implement the research project as well as time to build relationships with community members, rather than having such as rushed experience. Future researchers she incorporate more time as needed.

Second, the understanding of one another's roles in the research process could have been improved with more time, open communication, and clarity. Previous researchers have also raised this issue in the CBRE context (Flicker et al., 2008). With more clarity, my feedback could have been incorporated into the research process, particularly with member checking. There was limited involvement of participants in the member checking process or input into the research process in general due to several factors: my limited CBRE experience, limited time to forge relationships, and participants limited knowledge or experience with research and therefore tentativeness to provide input to the project. As a result, there was an inequitable distribution of power and control in research discussions and decisions (Israel et al., 1998). In addition to taking more time to build relationships, future research projects should consider collaboratively creating a memorandum of understanding for all those involved.

Support Group Flyer (September 2012)



For More Information…

Please contact the *Coaching Families* office to learn more:

- Address:

  #2, 9137 Jasper Ave
  Edmonton, AB
  T5H 3T3

- Phone:

  (780) 477-1999

This information about caregivers' experiences is based on a collaborative research study conducted by:

Katherine Roger & Dr. Christina Rinaldi,
Department of Educational Psychology,
University of Alberta
&
Denise Plesuk & Sharon Schultz,
Catholic Social Services FASD Programs

50 Years CHANGING LIVES
Catholic Charities
Catholic Social Services
Sign of Hope

UNIVERSITY OF ALBERTA

Coaching Families'

Support Group

September 2012

Coaching Families' Support Group

- *Coaching Families* helps families learn about and respond to the needs of their of their children (up to age 18) who are affected by or strongly suspected of being affected by Fetal Alcohol Spectrum Disorders (FASD)
- *Coaching Families* holds support group & information sessions monthly

Come meet other parents of kids with FASD!

Overview

- Typically held one Wednesday of each month from 9 am to noon
- Please contact your *Coaching Families* mentor for specific dates and times
- Different information sessions typically held each month
- For example, previous information sessions have included:
    - FASD 101
    - FASD & Youth Justice
    - Respite & Self Care

Caregivers' Experiences of the Support Group

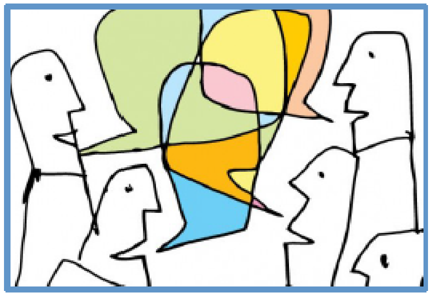
"It gives you a **venue to talk** and to hear others' stories and know that you're **not alone**. That helps so much."

"I would definitely **recommend** it"

"It's **definitely worth going to.**"

"There's lots of **information** that gets shared."

"I love **hearing their stories**… because it gives me so much **hope**."



"I think it's a **pretty good place to be**"

"**Friendship** and **support.**"

"You can voice your **opinion** and we're going to listen… It's like a **sounding board** that can help you with the daily issues that come up."

"It's just so great to hear people talk about the same things. To be with like-minded people that **aren't going to judge**, cause you're **all in the same boat**."

"It gives you **guidance**."

"Guidance, and **reassurance** – reassurance that you're **not alone**."

Appendix B: Overview of the Psychoeducational Support Group

Brief description:

Target audience: Adoptive and kinship caregivers of children aged 5 to 18 years who are diagnosed or suspected of having FASD

Number of participants: 6 caregivers (3 included in multiple case study)

Mode of presentation: Open discussions, structured discussions, and presentations.

Number of sessions: 5

Frequency of sessions: Monthly

Length of sessions: 3 hours

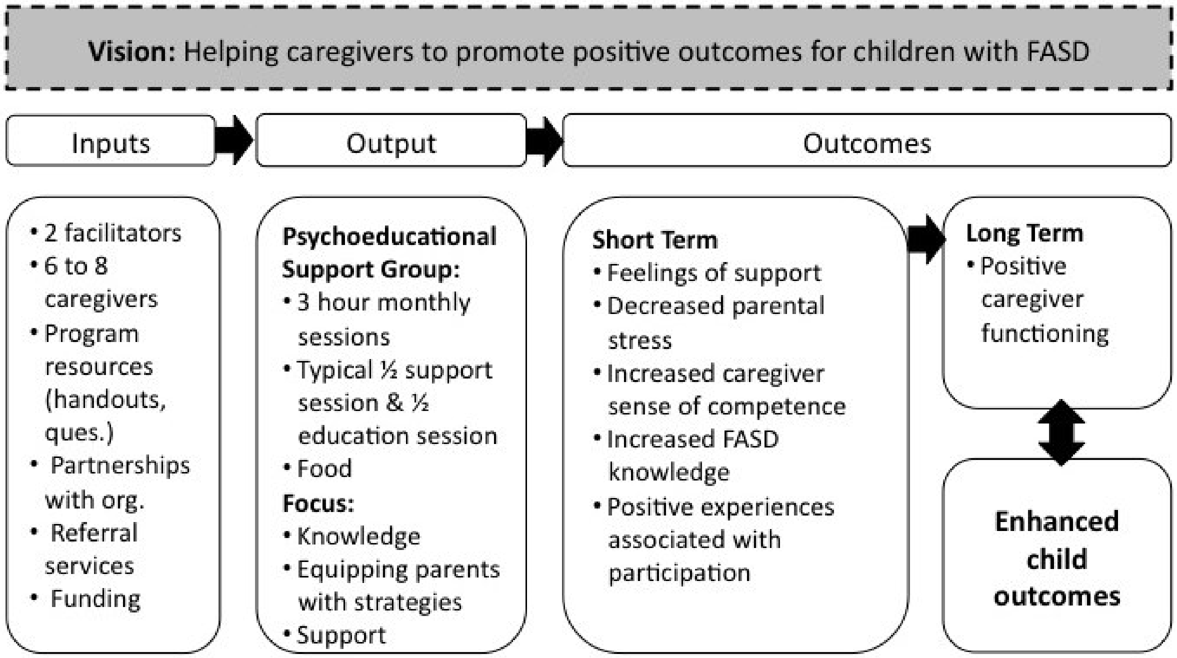
General overview:
Open conversation with food and refreshments (10 minutes)
Introduction of facilitators and previous of current week (5 minutes)
Open discussions (60 minutes)
Break with food and refreshments (10 minutes)
Information sessions & semi-structured discussions (60-90 minutes)
Wrap-up & debrief (ending with one positive thing; 10 minutes)

Weekly information sessions:
Time 3: Self-care and massages at MaKami College (February, 2012)
Time 4: FASD & Youth Justice, presented by Nadine Meikle (March, 2012)
Time 5: Alberta Caregivers Association, presented by Rachelle Giest (April, 2012)
Time 6: Support Group only (May, 2012)
Time 7: End of the Year Luncheon (April, 2012)

Previous topics:
"FASD 101," presented by Leca Rogozinsky, Edmonton Fetal Alcohol Network (April, 2011)
Respite services by SKILLS (October, 2011)
Holiday luncheon (December, 2011)

Food and refreshments were provided. Childcare and transportation were not provided.

Concise Program Logic Model



UNIVERSITY OF ALBERTA

Department of Educational Psychology
Faculty of Education

6-102 Education North
Edmonton, Alberta, Canada T6G 2G5

www.ualberta.ca

Tel: 780.492.5245
Fax: 780.492.1318

Appendix C: Information Letter

Study: Caregivers' Experiences of a Psychoeducational Support Group for Caregivers of Children with FASD

Dear Parent/Caregiver/Guardian,
Would you like to participate in a study about *Coaching Families'* (a Catholic Social Service Program) parent support group? We want to hear your thoughts about the support group and about being a parent of a child with Fetal Alcohol Spectrum Disorders (FASD)? We want to learn from you about how to improve support groups for parents.

I am a PhD student in School Psychology at the University of Alberta. I will be supervised by Dr. Christina Rinaldi. She is a professor who has a lot of experience working with parents and families.

Who can participate?

You can participate if you are a parent, caregiver, or guardian of a child or adolescent diagnosed or suspected of having FASD and actively participate in *Coaching Families'* support group.

What will I have to do?

If you choose to participate in the study, you will be asked to complete three components over 6 to 8 months:

> *Questionnaires:* You will be asked to fill out two sets of questionnaires. Each set will take approximately 30 minutes. The first set will be completed shortly after you decide to participate. The second set will be done after about 6-8 support group sessions. Both sets will include questions on parent stress, parent self esteem, social support, and quality of life. The first set will also include general family questions (i.e., child's age). The second set will also ask you to rate components of the support group (i.e., helpful topics).
>
> *Interviews:* You will be asked to complete two interviews. The first interview will occur shortly after you complete the first set of questionnaires. The second interview will happen after the second set of questionnaires. Both interviews will be recorded. Examples of topics covered in the interview include: What services and programs you have found helpful? What aspects of the support group have you found beneficial? Each interview will take approximately 1-2 hours over one or two sessions at a place and time that is convenient for you.
>
> *Feedback cards:* Before the beginning of 6-8 support group sessions, you will be asked to fill out an index card about how you have felt the previous week.

What are the benefits and risks of participating?

You will receive a $25 Safeway gift card after the first set of questionnaires and interviews as a thank you for your time. You will receive another $25 Safeway gift card at the end of the study. You will be able to directly inform changes to Coaching Families' support group by participating in the study. You can also hear about the results of the study if you like.

At times, it may be difficult to talk about your experiences of being a parent of a child with FASD and participating in the support group, and you may experience feelings of stress, sadness, and grief. Please let the researcher know if there is a question that you do not want to answer; you are not obligated to answer any question you don't want to.

Do I have to participate?

You are under no obligation to participate in this study. Participation is completely voluntary. This means everyone will respect your decision of whether or not you want to participate in the study. Your participation will not affect your involvement in any programming provided by *Coaching Families*. Even if you agree to participate, you can withdraw at any time. You are not obligated to answer any questions that you do not want to answer.

Will my information be kept private?

Your name will only appear on the signed Consent Form, which will be kept in a locked cabinet at the Coaching Families offices separate from the study data. Only the Coaching Families supervisors and myself will have access to the locked cabinet. Your name will not appear on anything else you give us as part of the study. You will have an ID number and be asked to choose a false name that will be used on any information. Information with no identifying elements will be kept in a locked cabinet at the University of Alberta. Only myself, my supervisor, and the study team (i.e., two Coaching Families supervisors) will have access to the study information. I will ask the *Coaching Families* team to help me analyze the information. Electronic recordings of the interviews will be kept on a digital memory disk (USB) in a locked cabinet and will be password protected. The information will be kept for a minimum of 5 years after the study is finished and then it will be destroyed.

Your involvement in this study and the information gathered will be kept confidential, with the exception of any instance/evidence of current child abuse, which we would be required to report by law.

How will my information be used?

The findings of the study will be shared with people working with parents of children with FASD, including the Coaching Families team. It will also be shared with the participants of the study. The results will also be presented and written up as part of my PhD program in School Psychology. It may also be presented at academic conferences and in journals. No names or identifying information will be included when the results of the study are shared.

Who can I contact if I have additional questions?

Please contact Katherine Roger at 780-700-5638 or kroger@ualberta.ca if you have any questions or concerns.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Thank you for your time.

Sincerely,

__________________________	__________________________
Katherine Roger, M.Ed. 6-102 Education North University of Alberta Edmonton, AB T6G 2G5 kroger@ualberta.ca 780-492-5624	Christina Rinaldi, Ph.D., R. Psych. 845 Education South University of Alberta Edmonton, AB T6G 2G5 crinaldi@ualberta.ca 780-492-3751

UNIVERSITY OF ALBERTA
Department of Educational Psychology
Faculty of Education
6-102 Education North
Edmonton, Alberta, Canada T6G 2G5
www.ualberta.ca
Tel: 780.492.5245
Fax: 780.492.1318

Appendix D: Consent Form

I, ____, hereby
(print name of Parent/Caregiver/Guardian)

☐ Consent
☐ Do not consent

To have **Katherine Roger** or a trained member of the research team contact me for the following research activities:

☐ Questionnaires to complete about parent stress, parent self esteem, social support, quality of life, rate components of the support group, and general family information.
☐ Interview me twice for approximately 1 to 2 hours over 1 or 2 sessions at a place and time that is convenient for me.
☐ Audio record the interviews.
☐ Feedback cards before 5 to 8 support group sessions to fill out about how I have been doing during the last week or so.

I understand that:

- I may withdraw from the study at any time. It will not affect my involvement in any program or service.

- All information gathered will be treated confidentially. It will only be used for the sole purpose of research and informing interventions.
- Any information that identifies me will be destroyed upon completion of this research. Please note: data will be kept for a minimum of 5 years after the study is finished.
- I will **not** be identified in any documents resulting from this research.

I also understand that the results of this research will be used only in the following cases:

- Presentations, reports, and articles for other researchers, educators, parents, and FASD programs.
- General information sessions with service providers.
- A written and oral dissertation for Katherine Roger's PhD degree requirements.

Name of Parent/Caregiver/Guardian: _____________________________________

Signature of Parent/Caregiver/Guardian: __________________________________

Date signed: ____

For further information, please contact Katherine Roger, MEd, University of Alberta, Department of Educational Psychology, Edmonton, AB, T6G 2G5, kroger@ualberta.ca or (780) 492-5624

Appendix E: Recruitment Letter

Have you attended or are you interested in attending the Coaching Families parent support group? *We want to hear from you!*

You are invited to participate in a study about parents' experiences of participating in Coaching Families' support group. We want to learn about your experiences in order to improve the support group and other services for parents.

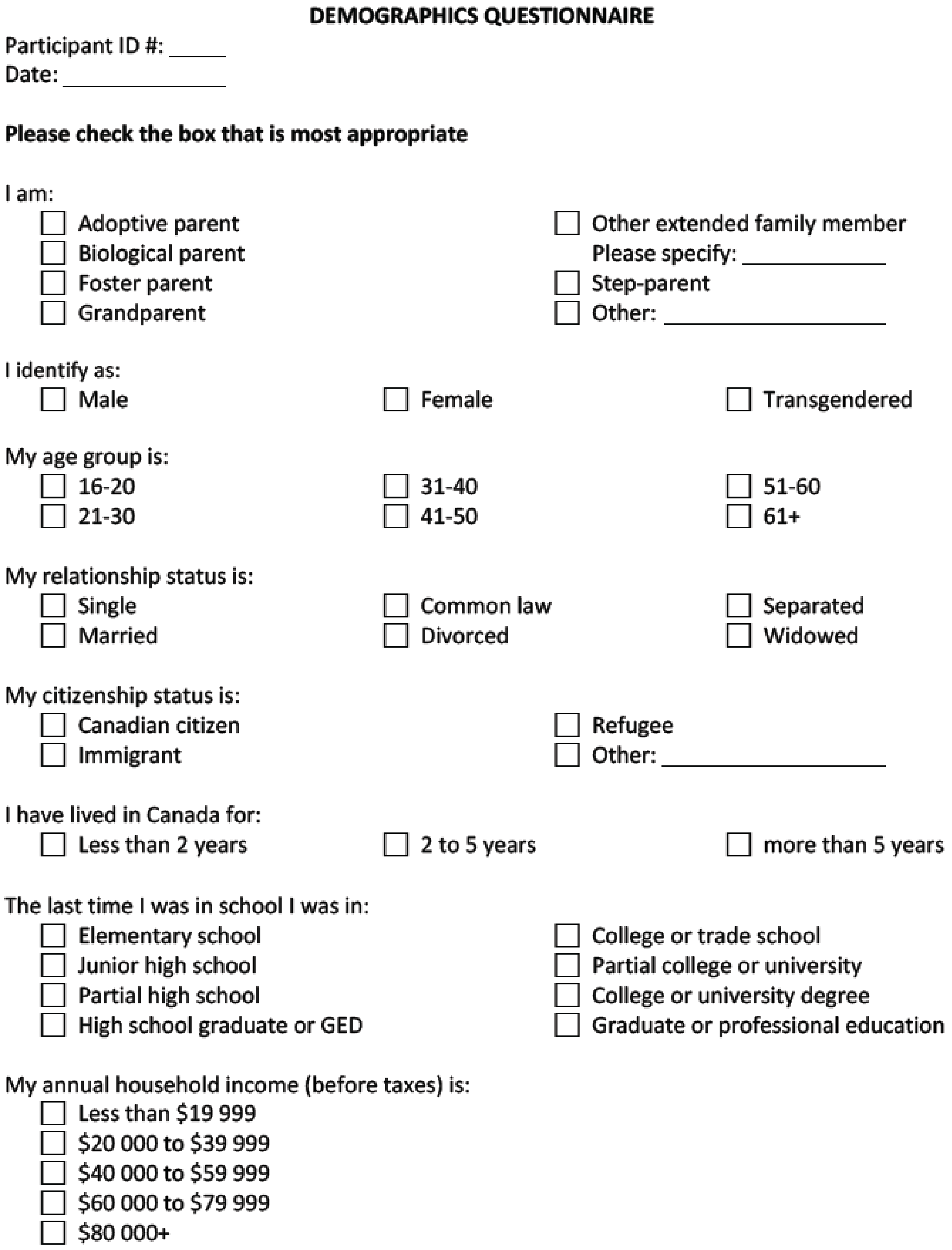
If you'd like some more information or would like to be involved please contact:

Katherine Roger or Dr. Christina Rinaldi
(780) 492-5624
kroger@ualberta.ca

UNIVERSITY OF ALBERTA

50 Years
CHANGING LIVES
Catholic Charities
Catholic Social Services
Sign of Hope

Appendix F: Demographics Questionnaire



DEMOGRAPHICS QUESTIONNAIRE

Participant ID #: _____
Date: ______________

Please check the box that is most appropriate

I am:
- ☐ Adoptive parent
- ☐ Biological parent
- ☐ Foster parent
- ☐ Grandparent
- ☐ Other extended family member
  Please specify: ____________
- ☐ Step-parent
- ☐ Other: ___________________

I identify as:
- ☐ Male
- ☐ Female
- ☐ Transgendered

My age group is:
- ☐ 16-20
- ☐ 21-30
- ☐ 31-40
- ☐ 41-50
- ☐ 51-60
- ☐ 61+

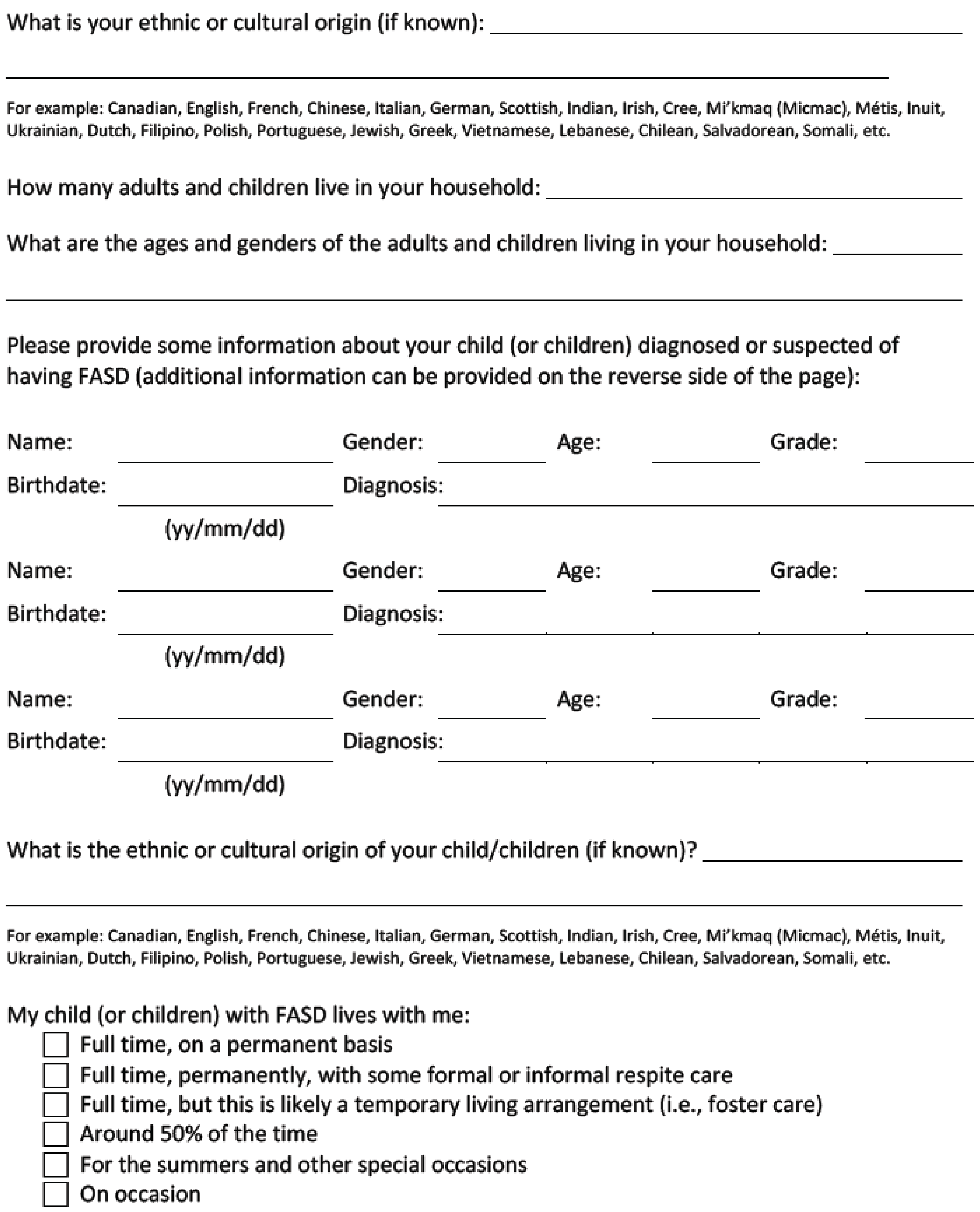
My relationship status is:
- ☐ Single
- ☐ Married
- ☐ Common law
- ☐ Divorced
- ☐ Separated
- ☐ Widowed

My citizenship status is:
- ☐ Canadian citizen
- ☐ Immigrant
- ☐ Refugee
- ☐ Other: ___________________

I have lived in Canada for:
- ☐ Less than 2 years
- ☐ 2 to 5 years
- ☐ more than 5 years

The last time I was in school I was in:
- ☐ Elementary school
- ☐ Junior high school
- ☐ Partial high school
- ☐ High school graduate or GED
- ☐ College or trade school
- ☐ Partial college or university
- ☐ College or university degree
- ☐ Graduate or professional education

My annual household income (before taxes) is:
- ☐ Less than $19 999
- ☐ $20 000 to $39 999
- ☐ $40 000 to $59 999
- ☐ $60 000 to $79 999
- ☐ $80 000+



What is your ethnic or cultural origin (if known): ______________________________

____

For example: Canadian, English, French, Chinese, Italian, German, Scottish, Indian, Irish, Cree, Mi'kmaq (Micmac), Métis, Inuit, Ukrainian, Dutch, Filipino, Polish, Portuguese, Jewish, Greek, Vietnamese, Lebanese, Chilean, Salvadorean, Somali, etc.

How many adults and children live in your household: ___________________________

What are the ages and genders of the adults and children living in your household: ________

____

Please provide some information about your child (or children) diagnosed or suspected of having FASD (additional information can be provided on the reverse side of the page):

Name: ______________ Gender: ________ Age: ________ Grade: ________

Birthdate: ______________ Diagnosis: ______________________________

(yy/mm/dd)

Name: ______________ Gender: ________ Age: ________ Grade: ________

Birthdate: ______________ Diagnosis: ______________________________

(yy/mm/dd)

Name: ______________ Gender: ________ Age: ________ Grade: ________

Birthdate: ______________ Diagnosis: ______________________________

(yy/mm/dd)

What is the ethnic or cultural origin of your child/children (if known)? ________________

____

For example: Canadian, English, French, Chinese, Italian, German, Scottish, Indian, Irish, Cree, Mi'kmaq (Micmac), Métis, Inuit, Ukrainian, Dutch, Filipino, Polish, Portuguese, Jewish, Greek, Vietnamese, Lebanese, Chilean, Salvadorean, Somali, etc.

My child (or children) with FASD lives with me:

- ☐ Full time, on a permanent basis
- ☐ Full time, permanently, with some formal or informal respite care
- ☐ Full time, but this is likely a temporary living arrangement (i.e., foster care)
- ☐ Around 50% of the time
- ☐ For the summers and other special occasions
- ☐ On occasion

How long has your child (children) been in your care: ________________________________

Please list the kinds of service providers that have been involved with your child (including specialists, occupational therapists, social workers, respite, etc.): ____________________

____

____

What programs, if any, do you or your child/children currently attend? ______________

____

____

How long have you or your child/children attended these programs? __________________

____

____

Please indicate your overall experience with the services or programs your family has been involved with:

- ☐ I feel I am well connected and the services or programs meet the needs of my family
- ☐ I am involved with some services or programs, which meet some of the needs of my family
- ☐ I am involved with some services or programs, but I have to use a lot of energy to get the needs of my family met
- ☐ I am involved with a few services or programs, but they only marginally meet the needs of my family
- ☐ I am involved with no services or programs
- ☐ Other: ____

Any additional comments, questions, or information: ______________________________

____

____

____

____

____

____

____

____

Appendix G: Rating Scale

RATING SCALE

Participant ID #: _____
Date: ______________

Please circle an answer that best reflects your feelings about each statement

1. Overall, how would you rate this group?

1	2	3	4	5
Poor		*Fair*		*Excellent*

2. How satisfied were you with how well this group met your current needs as a caregiver of a child with FASD?

1	2	3	4	5
Not at all satisfied		*Somewhat satisfied*		*Very satisfied*

3. How satisfied are you with the amount of information that was presented?

1	2	3	4	5
Not at all satisfied		*Somewhat satisfied*		*Very satisfied*

4. Do you believe the information presented in the group helped you to deal more effectively with your child with FASD?

1	2	3	4	5
Not at all helpful		*Somewhat helpful*		*Very helpful*

5. Was the information presented in ways that engaged your interest?

1	2	3	4	5
No, not at all engaging		*Somewhat engaging*		*Yes, very engaging*

6. Did this group help you to learn about services or programs in the community?

1	2	3	4	5
No, not at all		*Somewhat*		*Yes, definitely*

7. Do you feel learning about other parents' experiences helped you in your own life?

1	2	3	4	5
No, not at all		*Somewhat*		*Yes, definitely*

8. Was childcare ever a barrier for you attending the group?

1	2	3	4	5
No, not at all		*Somewhat*		*Yes, definitely*

9. What type of session do you most prefer:

1	2	3
Support group (alone)	*Support group & information session*	*Information session (alone)*

10. Please rate the "helpfulness" of each session:

a. February session: Massages at MaKami College.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

b. March session: FASD & Youth Justice, presented by Nadine Meikle.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

c. April session: Alberta Caregivers Association, presented by Rachelle Giest.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

d. May session: Only support group, no information session.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

e. June session: Year End Luncheon.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

11. Please rate the "helpfulness" of some past sessions, if you were able to attend:

a. April, 2011 session: FASD presentation ("FASD 101"), presented by Leca Rogozinsky.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

b. October, 2011 session: Respite services by SKILLS, presented by Carolina Anaya.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

c. December, 2011 session: Holiday luncheon.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

d. Other: ________________________________

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

e. Other: ________________________________

12. How "helpful" was the group for the aspects listed below? Please circle your answer:

a. Finding out how others are dealing with their problems.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

b. Getting a chance to meet people with similar problems.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

c. Sharing feelings with other group members.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

d. Getting support from other group members.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

e. Learning practical solutions to everyday problems.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

f. Learning things to do to feel better *yourself*.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

g. Feeling less isolated and alone.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

h. Feeling less stressed as a parent.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

i. Feeling more confident as a parent.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

j. Gathering information about social and community services.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

k. Learning where to get more help when you need it.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

m. Learning how to get along with other members of your family.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

n. Learning about strategies to help your child with FASD.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

o. Being able to share challenges.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

p. Being able to share successes.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

q. Meeting new people.

1	2	3	4	5
Not helpful		*Somewhat helpful*		*Very helpful*

13. How *supported* did you feel in this group?

1	2	3	4	5
Not at all supported		*Somewhat supported*		*Very supported*

14. How *understood* did you feel in this group?

1	2	3	4	5
Not at all supported		*Somewhat supported*		*Very supported*

15. If you needed help in the future, would you come back to the group?

1	2	3	4	5
No, definitely not		*Maybe*		*Yes, definitely*

Why or why not? ____

____

____

16. Would you recommend this group to other caregivers of children with FASD?

1	2	3	4	5
No, definitely not		*Maybe*		*Yes, definitely*

Why or why not? ____

____

____

17. What did you *like best* about the psychoeducational support group?____________________

18. What did you *like least* about the psychoeducational support group?____________________

19. What did you find the *most helpful* about the psychoeducational support group?__________

20. What did you find *least helpful* about the psychoeducational support group?_____________

21. If you did not attend all the support group sessions, why did you not attend? _____________

22. Can you describe an experience that you dealt with differently because of what you have learned from the group? If so, please describe it briefly. ______________________________

23. Do you have any suggestions for ways in which the group could be improved?____________

24. Other comments? (Use back of sheet if needed)_____________________________________

Appendix H: Coaching Families Stress (CFS) Scale

	Never	Rarely	Sometimes	Frequently	Constantly
1. I feel tired/exhausted	0	1	2	3	4
2. We are arguing about how to parent this child	0	1	2	3	4
3. I worry about not being able to cope	0	1	2	3	4
4. I worry that this will get harder as my child gets older	0	1	2	3	4
5. I worry about my health	0	1	2	3	4
6. I feel hopeless about our situation	0	1	2	3	4
7. I worry about how this will affect my other children	0	1	2	3	4
8. I avoid participating in family/social gatherings with this child	0	1	2	3	4
9. a) I have difficulty accessing respite resources	0	1	2	3	4
b) I am uncomfortable using respite resources	0	1	2	3	4
11. I worry about our/my financial situation	0	1	2	3	4
12. I lay awake at night and worry	0	1	2	3	4
13. I have difficulty accessing resources/supports in the community	0	1	2	3	4
14. I worry that I am running out of ideas on how to parent this child	0	1	2	3	4
15. I feel frustrated with the school system	0	1	2	3	4
16. I have lost my sense of humour	0	1	2	3	4
TOTAL					

Appendix I: Parenting Sense of Competence Scale (PSOC)

(Gibaud-Wallston & Wandersman, 1978; Johnson & Mash, 1989)

Please rate the extent to which you agree or disagree with each of the following statements.

Strongly Disagree	Somewhat Disagree	Disagree	Agree	Somewhat Agree	Strongly Agree
1	2	3	4	5	6

1. 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. 1 2 3 4 5 6

2. Even though being a parent could be rewarding, I am frustrated now while my child is at his / her present age. 1 2 3 4 5 6

3. I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot. 1 2 3 4 5 6

4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated. 1 2 3 4 5 6

5. My mother was better prepared to be a good parent than I am. 1 2 3 4 5 6

6. I would make a fine model for a new parent to follow in order to learn what she would need to know in order to be a good parent. 1 2 3 4 5 6

7. Being a parent is manageable, and any problems are easily solved. 1 2 3 4 5 6

8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one. 1 2 3 4 5 6

9.	Sometimes I feel like I'm not getting anything done.	1	2	3	4	5	6
10.	I meet my own personal expectations for expertise in caring for my child.	1	2	3	4	5	6
11.	If anyone can find the answer to what is troubling my child, I am the one.	1	2	3	4	5	6
12.	My talents and interests are in other areas, not being a parent.	1	2	3	4	5	6
13.	Considering how long I've been a parent, I feel thoroughly familiar with this role.	1	2	3	4	5	6
14.	If being a parent of a child were only more interesting, I would be motivated to do a better job as a parent.	1	2	3	4	5	6
15.	I honestly believe I have all the skills necessary to be a good parent to my child.	1	2	3	4	5	6
16.	Being a parent makes me tense and anxious.	1	2	3	4	5	6
17.	Being a good parent is a reward in itself.	1	2	3	4	5	6

Appendix J: Example of Pre-Intervention Interview Protocol (Time 2)

INTERVIEW QUESTIONS

Participant #27

GENERAL QUESTIONS AND LIVED EXPERIENCES

Employment

1. Does your partner work? If so, what work do you/they do?
2. Tell me a little bit about the story of your family. (Under what circumstances did they come into your care.)

Strengths/needs

3. What do you believe are your strengths as a caregiver of a child/children with FASD?
4. What are your needs as a caregiver of child/children with FASD?
5. Tell me about a time when you felt successful being a caregiver? Tell me about a time when you have not felt successful being a caregiver?

SERVICES

Kind

6. What services or programs have you accessed to help your family and child with FASD?
    a. In your questionnaires you mentioned: OT, SLP, psychologist, social worker, respite providers, coaching families, teachers, early ed, tutors
    b. You mentioned before that you have someone helping at home with cleaning and the kids. Can you tell me a little about that service (when it started, etc.)?
7. How do you find out/learn about services or programs?

Access

8. What has helped you to become well connected to services in the community?
9. What barriers have you faced in attempts to access services?
    a. Tell me about a time when you tried to attend a program or access services and something stopped you?
    b. Diagnosis for FASD – are you attempting to receive a diagnosis for your children that you suspect to have FASD? Why or why not?
    c. In particular, has access to childcare been a barrier for you in attempts to access services? Why or why not?

Helpful/not helpful

10. What services have been helpful and impactful? Not helpful or impactful for you?

Gaps

11. What have you perceived are gaps in services for yourself as a caregiver of children with FASD?
    a. You mentioned earlier that the information sessions that you have attended regarding FASD has only "scratched the surface" or are superficial. Can you tell me a bit more about that and your experience?

STRESS

Helps/makes it difficult

12. You list that you are particularly stressed with worrying about your health and feeling tired or exhausted all the time? Can you tell me a bit more about that and how you cope?
13. What helps you deal with stress? What do you do to deal with stress? What doesn't help you deal with stress?
14. What do you feel helps you to be a good caregiver for a child/children with FASD? What makes it difficult to be a caregiver of a child/children with FASD?
15. How do you cope when dealing with the difficulties of raising a child with FASD?
    a. What things to do you and when? Who do you call on when you are stressed or need someone to talk to? Who do you vent to?
16. Tell me about a time when you were very stressed being a caregiver? Tell me about a time when you weren't stressed being a caregiver?

Services

17. Have any services helped (or not) you deal with stress? If so, how?

FEELINGS OF COMPETENCE

Helps/hinders

18. What helps you feel competent and self confident in your role of raising a child with FASD? What hinders?
    a. Tell me about a time when you felt confident being a caregiver? Not competent?
19. One of the questionnaires indicates that you are confident at being a caregiver for your children. How do you think that affects the stress that you feel as a caregiver? How do you think stress affects your feelings of competence or self-esteem related to raising a child with FASD?

Knowledge

20. What knowledge of FASD has been helpful for you to raise a child with FASD?
21. Why has this information been helpful?
22. What information are you seeking about FASD? Why are you seeking this information?
23. Tell me about a time when you have learned information regarding FASD and is has been very helpful?

SOCIAL SUPPORT AND RESPITE CARE

General

24. What social supports do you have to help raise their child with FASD?
    a. You mentioned that your partner has been very supportive. Can you tell me more about this?

   b. You've also mentioned some professionals or professional agencies (doctor, helpers, agencies) have been helpful. Can you tell me more about that?
25. How do social supports help you take care of a child with FASD?
26. You mentioned that social clubs/groups are helpful. Which social clubs?

Respite

27. How is respite helpful?
    a. Tell me a time when respite was helpful for you?
28. Has respite helped with feeling stressed?
    a. If so, how?
29. How has social support helped you deal with stress?

FAMILY QUALITY OF LIFE

General

30. Has raising a child with FASD affected your quality of life? If so, how?
31. How does your stress/sense of competence/support affect your quality of life?
32. What services have improved or not improved caregivers' quality of life?
    a. How did services help to improve your quality of life?
    b. Tell me about a time when a service or program has improved or not improved your quality of life?

PSYCHOEDUCATIONAL GROUPS

Helpful/not helpful

33. What aspects of support groups have you found helpful? Not helpful?
34. Why have these aspects been helpful or not helpful?
    a. Tell me about a time when attending a support group has been helpful?

Introduction

35. What information or educational sessions have been helpful or not helpful?
    a. Why were these sessions helpful or not helpful?
    b. Tell me about a time when an information or educational session has been helpful or not helpful?

Attendance

36. Why did you first begin to attend support groups?
37. What keeps you coming back?
38. What could be improved in the support group?

MENTOR AND SUPPORT GROUP

---

39. Did a mentor encourage you to come to the support group? What would influence you to come to the support group? What factors?

Appendix K: Example of Post-Intervention Interview Protocol (Time 9)

INTERVIEW QUESTIONS

Participant #27

GENERAL QUESTIONS AND CHECK-IN

1. How have things been during the last 5 months?
    a. Daughter, oppositional
        i. Mentioned one or two children have been having a bad cycle (two kids with ODD)
        ii. Can you explain the impact on the other kids?
            1. A particular story?
    b. Still interested in being a mentor?
2. It seemed things were stressful in May onward…

SUPPORT

3. Do you feel supported as a caregiver, either formally or informally?
    a. School
        i. Summer programming
    b. Respite
4. Questionnaire shows that professional support might have decreased…

SERVICES

5. Other services you have been accessing the last 5 months that have been helpful?
    c. Respite
    d. School
    e. Anything else?

STRESS

6. Do you feel you are stressed as a caregiver?
    f. Husband out of town
    g. Your own health
    h. Keeping things consistent
    i. Helping them be independent
7. Has how you deal with stress changed over the last 6 months?
    j. One questionnaire show that it has increased
        i. Is that what you've felt
8. PSI

    k. 92nd percentile – does this reflect what you feel you are experiencing? (Before 66th percentile)
9. Scale of 1 to 100.

SENSE OF CONFIDENCE AS A PARENT

---

10. Do you feel confident as a parent? Why or why not?
    l. Questionnaire shows that your confidence has increased in the last 5 months. Is this how you are feeling? Why do you think this is the case?
11. Knowledgeable?

QUALITY OF LIFE

---

12. Has your quality of life changed during the last 6 months? (decreased on questionnaires)

HELPFULNESS (OR NOT) OF THE SUPPORT GROUP

---

13. What keeps you coming back?
    m. Being a leader in the group
    n. "I believe the more people we support and are supported by us leads us to greater happiness and success" (Rating). Tell me more.
    o. Communication more with your husband, Nathan?
14. How have you found the support group helpful?
    a. Particular caregivers or particular interactions?
        i. Talking with Kristen
15. Can you tell me a particular time (story) that the support group has been helpful?
16. Have you felt that you have found out about services that are helpful? Why or why not?
17. How has it affected your:
    b. Stress levels
    c. Sense of confidence as a parent
    d. Feelings of support?
18. How have you found the support group not helpful?
    a. Any particular interactions? Horror stories?
19. What could be improved in the support group?
    p. Having a topic to discuss (February FF)
    q. Facilitation
    r. Music playing before we start or the facilitator welcoming people

---

LOOKING TO THE FUTURE & SUPPORT GROUP MARKETING

---

20. Indicated that you were not really satisfied with the amount of info presented at the support group. What would you like changed?
21. Other topics you think would be helpful for next year?

22. What would you want to tell other caregivers about the group?
    b. We're creating a flyer for other caregivers…

FINISHING UP

---

23. Anything else you would like to tell me about?
24. I will be writing about the experiences you have shared with me in presentations, posters, and my dissertation. What pseudonym would you like me to use for name?
25. Member checking.

Appendix L: Overview of Possible Primary and Secondary Topical Questions for Creating Interview Protocols

(Influenced by Olson, Rudo-Stern, & Gendler, 2011)

Pre-intervention questions

Lived experiences of caregivers of children with FASD

1. What do you believe are the strengths of caregivers raising children with FASD?
2. What are the needs of caregivers?
3. Tell me about a time when you felt successful being a caregiver?
4. Tell me about a time when you have not felt successful being a caregiver?
5. What are the protective factors for caregivers of children with FASD?
6. What are the risk factors?
7. How do you cope when dealing with the difficulties of raising a child with FASD? What things to do you and when?
8. What are your attitudes towards being a caregiver of a child with FASD? Has your attitudes changed over time? If so, how?
9. If you have more than one child, how does your parenting practices differ between children?
10. What services have you accessed to help your family and child with FASD?
11. What services have been helpful and impactful or not helpful or impactful for you?
12. What has helped you access services?
13. Can you tell me about a time when you accessed services?
14. What barriers have you faced in attempts to access services?
15. Tell me about a time when you tried to attend a program or access services and something stopped you?
16. In particular, has access to childcare been a barrier for you in attempts to access services? Why or why not?
17. What have you perceived are gaps in services for caregivers of children with FASD?

Feelings of stress

18. What are your experiences of stress?
19. Tell me about a time when you were very stressed being a caregiver?
20. Tell me about a time when you weren't stressed being a caregiver?
21. What helps or hinders you deal with stress?
22. What services have helped or hindered (or not) you deal with stress?
23. How did these things help or hinder your stress?

Feelings of competence

24. What helps you feel competent and self confident in your role of raising a child with FASD? What hinders?
25. How do these things help or hinder your sense of competence?
26. Tell me about a time when you felt confident being a caregiver? Not competent?
27. What knowledge of FASD has been helpful for you to raise a child with FASD?
28. Why has this information been helpful?
29. What information are you seeking about FASD?
30. Why are you seeking this information?
31. Tell me about a time when you have learned information regarding FASD and is has been very helpful?
32. How do you think stress affects your feelings of competence or self-esteem related to raising a child with FASD?

Social support and respite care

33. What social supports do you have to help raise their child with FASD?
34. How do social supports help you take care of a child with FASD?
35. What types of respite are most beneficial for you?
36. How is respite helpful?
37. Tell me a time when respite was helpful for you?
38. Has respite helped with feeling stressed? If so, how?
39. How has social support helped you deal with stress?

Family quality of life

40. How does raising a child with FASD affect your overall quality of life?
41. How does your stress /sense of competence/support affect your quality of life?
42. What services have improved or not improved caregivers' quality of life?
43. How did services help to improve your quality of life?
44. Tell me about a time when a service or program has improved or not improved your quality of life?

Support groups

45. What aspects of support groups have you found helpful or not helpful?
46. Why have these aspects been helpful or not helpful?
47. Tell me about a time when attending a support group has been helpful?
48. Why did you first begin to attend support groups?
49. What was your first experience like attending a support group?

Psychoeducational groups

50. What information or educational sessions have been helpful or not helpful?
51. Why were these sessions helpful or not helpful?
52. Tell me about a time when an information or educational session has been helpful or not helpful?

Psychoeducational support groups

53. What aspects of a psychoeducational support group would be?
54. Why would these elements be helpful?
55. What aspects would not be helpful for a psychoeducational support group?

Post-intervention questions

Psychoeducational support group

56. What were your experiences of participating in the psychoeducational support group?
57. What elements were helpful and/or impactful?
58. How were these elements helpful and/or impactful?
59. What elements of the psychoeducational support group were not helpful?
60. Why were elements not helpful?
61. What did you like most about the group?
62. What did you like least about the group?

Feelings of stress

63. How did the psychoeducational support group affect your levels of stress?
64. What were your experiences of stress while participating in the psychoeducational support group?
65. What elements helped or hindered your level of stress?
66. Tell me about an experience about your level of stress while participating in the psychoeducational group?

Feelings of competence

67. How did the psychoeducational support group affect your feelings of competence?
68. What were your feelings of competence while participating in the psychoeducational support group?
69. What elements helped or hindered you feeling of competence?
70. How did the psychoeducational support group affect your knowledge of FASD?
71. What aspects helped or hinder your knowledge of FASD?
72. How did your level of knowledge affect your feelings of competence?

73. Tell me about a time during the psychoeducational support group that you felt a sense of competence of being a caregiver?

Social support and respite

74. How did the psychoeducational support group affect your feelings of social support?
75. What were your experiences of support while participating in the psychoeducational support group?
76. Please tell me about a specific experience?
77. What were your experiences of respite while participating in the psychoeducational support group?
78. Please let me about a specific experience?
79. How did social support and respite affect your feelings of stress and competence?

Family quality of life

80. How did the psychoeducational support group affect your family's quality of life?
81. What was your quality of life while participating in the psychoeducational support group?
82. What was the relationship between your feelings of stress/sense of competence/social support/respite and quality of life?

Appendix M: Feedback Form

Participant: __
Month: _____

How well have you been doing (e.g., levels of stress, coping, quality of life) since the last support group session in May?

On a scale of 1 to 10, please indicate how well you have been doing in general since the last support group session in May?

1	2	3	4	5	6	7	8	9	10
Very Bad									Very Good

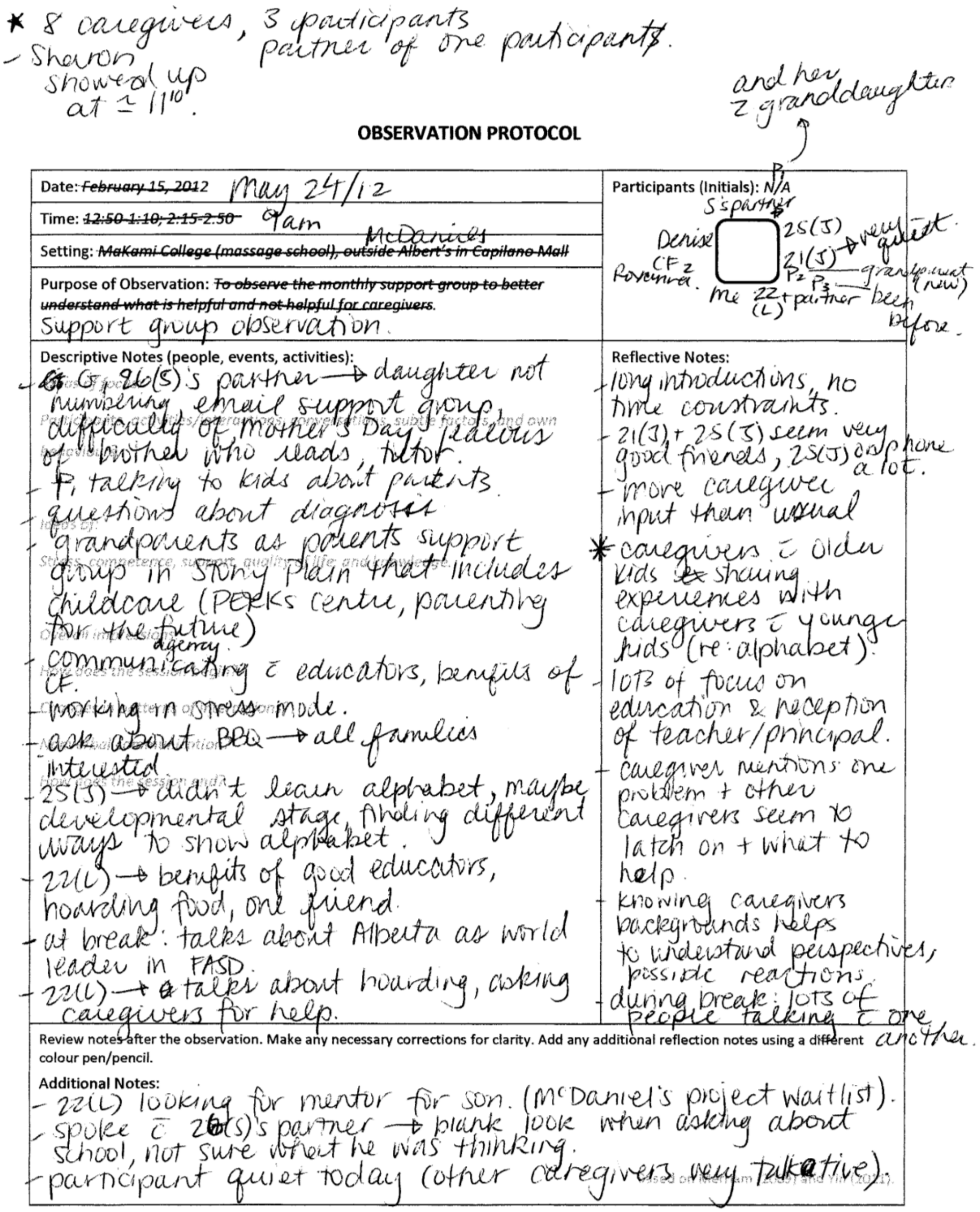
Did the last support group in May help you to be a caregiver to your child with FASD?
If so, how? If not, what would make it more helpful?

Please place back in the envelope provided. Thank you!

Appendix N: Observation Protocol

Date:	Participants (Initials):
Time:	
Setting:	
Purpose of Observation:	
Descriptive Notes (people, events, activities): *Areas of focus:* *Participants, activities/interactions, conversations, subtle factors, and own behaviours.* *Ideas of:* *Stress, competence, support, quality of life, and knowledge.* *Overall impressions:* *How does the session begin?* *Changes in patterns of interactions?* *Nonverbal communication?* *How does the session end?*	Reflective Notes:
Review notes after the observation. Make any necessary corrections for clarity. Add any additional reflection notes using a different colour pen/pencil. Additional Notes: Based on Merriam (2009) and Yin (2011).	

Appendix O: Example of Observation Notes



* 8 caregivers, 3 participants
partner of one participants.
- Sharon
showed up
at ≐ 11¹⁰.

and her
2 granddaughter

OBSERVATION PROTOCOL

Date: ~~February 15, 2012~~ May 24/12

Time: ~~12:50-1:10; 2:15-2:50~~ 9am

Setting: ~~MaKami College (massage school), outside Albert's in Capilano Mall~~ McDaniels

Purpose of Observation: ~~To observe the monthly support group to better understand what is helpful and not helpful for caregivers.~~
Support group observation.

Participants (Initials): ~~N/A~~ P₁
S's partner
Denise
CF 2
Roxanna.
25(J)
21(J) → very quiet.
P₂
P₃ — grandparent (new)
Me
22 (L) + partner been before.

Descriptive Notes (people, events, activities):
- ~~G~~ G 26(S)'s partner → daughter not numbering email support group, difficulty of Mother's Day jealous of brother who reads, tutor.
- P₁ talking to kids about parents
- questions about diagnosis
- grandparents as parents support group in Stony Plain that includes childcare (PERKS centre, parenting for the future)
- communicating ē educators, benefits of CF. agency.
- working in stress mode.
- ask about BBQ → all families interested
- 25(J) → didn't learn alphabet, maybe developmental stage, finding different ways to show alphabet.
- 22(L) → benefits of good educators, hoarding food, one friend.
- at break: talks about Alberta as world leader in FASD.
- 22(L) → talks about hoarding, asking caregivers for help.

Reflective Notes:
- long introductions, no time constraints.
- 21(J) + 25(J) seem very good friends, 25(J) on phone a lot.
- more caregiver input than usual
* caregivers ē older kids ~~ex~~ sharing experiences with caregivers ē younger kids (re: alphabet).
- lots of focus on education & reception of teacher/principal.
- caregiver mentions one problem + other caregivers seem to latch on + what to help.
- knowing caregivers backgrounds helps to understand perspectives, possible reactions.
- during break: lots of people talking ē one another.

Review notes after the observation. Make any necessary corrections for clarity. Add any additional reflection notes using a different colour pen/pencil.

Additional Notes:
- 22(L) looking for mentor for son. (McDaniel's project waitlist).
- spoke ē 26(S)'s partner → blank look when asking about school, not sure what he was thinking.
- participant quiet today (other caregivers very talkative).

- discussion of food choices, dif. opinions of "junk" food, whether or not should be in the house.
- discussion of sugar and academic performance and hyperactivity
- I wonder how helpful this is... (?) away from issue.
- talking about not trying harder, but trying ~~diff~~ differently. If you don't know what to do, just do something. Good philosophy for life.
- talked about diagnosis + education clinic.
- sharing info. about good schools, and highlighting importance of schools (support)
- keeping agendas.
- ending with one pos. thing.

Appendix P: Quantitative Questionnaire Descriptive and Raw Scores

	Case 1		Case 2		Case 3	
	Time 1	**Time 8**	**Time 1**	**Time 8**	**Time 1**	**Time 8**
Parenting Stress Index/Short Form (PSI/SF)[1]						
Parental Distress	85	60	55	82	65	65
Parent-Child Dysfunctional Interaction	99	97	96	99	90	97
Difficult Child	96	95	97	98	85	90
Total Stress	99	95	97	99	87	94
Coaching Families FASD Family Stress Scale (CFS)[2]						
Mean Item Response (0 [Never] to 4 [constantly])	1.4	0.9	1.4	1.5	1.6	1.7
Total Raw Score (out of 64)	22	15	23	24	25	28
Parent Sense of Competence Scale (PSOC)[3]						
Satisfaction Mean	3.2	3.3	3.2	3.9	3.2	2.0
Efficacy Mean	3.1	3.0	2.6	3.1	1.9	2.0
Mean Item Response	3.4	3.4	3.5	3.7	2.2	2.4
Total Score (out of 102)	58	58	59	64	37	40
Family Support Scale (FSS)[4]						
Kinship Mean	3.5	4.0	1.5	2.5	3.5	3.0
Partner Mean	2.3	2.0	3.3	4.7	0.0	0.0
Informal Mean	1.0	1.3	1.0	1.0	0.8	1.2
Program/ Organization Mean	3.0	2.0	1.5	2.5	1.0	2.3
Professional Mean	3.0	3.0	2	2.5	1.0	1.8
Informal Mean Total	2.1	2.0	1.7	2.3	1.1	1.5
Formal Mean Total	3.0	3.0	2.0	2.5	1.0	1.8
Mean Total	2.3	2.2	1.7	2.4	1.1	1.5
Total Score (out of 95)	20	29	33	45	20	29
Family Quality of Life Scale (FQOL)[5]						
Family Interactions Mean	4.2	4.2	3.7	3.3	4.2	4.7
Parenting Mean	3.8	4.0	3.5	3.8	4.8	4.8

Emotional Well-Being Mean	4.0	3.8	2.5	3.5	3.0	3.5
Physical/Material Well-Being	3.6	4.2	4.0	4.0	4.6	4.4
Disability-Related Support Mean	3.5	3.8	3.3	3.8	3.5	3.8
Total Mean	3.8	4.0	3.4	3.7	4.1	4.3
Total Score (out of 125)	96	100	86	92	103	108

[1] PSI scores are represented by percentiles. High Scores are scores at or above the 85th percentile. Clinically Significant Scores are scores at or above the 90th percentile.

[2] CFS items are rated on a five-point Likert scale from (0) Never to (4) Constantly)

[3] PSOC items were rated on a six-point Likert scale from (1) Strongly Disagree to (6) Strongly Agree.

[4] FSS items were rated on a five-point Likert scale from (1) Not At All Helpful to (5) Extremely Helpful.

[5] FQOL items were rated on a five-point Likert scale from (1) Very Dissatisfied to (5) Very Satisfied.

Appendix Q: Handout for Caregivers at End-of-Year BBQ (August 8, 2012)

A support group for caregivers of children FASD: *What are caregivers' experiences?*

Katherine Roger, Dr. Christina Rinaldi,
Dr. Cheryl Poth, & Dr. Jacqueline Pei
Department of Educational Psychology,
University of Alberta

Denise Plesuk & Sharon Schultz
Catholic Social Services
FASD Programs

Background

Children with FASD can experience a number of developmental and behavioural difficulties. Stable, nurturing homes can help the positive development of children with FASD. However, caregivers of children with FASD typically have higher levels of stress, which can affect the overall quality of life of a family.

Education and support groups have been found to be effective for helping caregivers to decrease stress. *Coaching Families* (a *Catholic Social Services* FASD program) has started a support group with information sessions for caregivers of children with FASD in Edmonton.

This study explored caregivers experiences of the *Coaching Families* support group. We wanted to learn what was (or was not) helpful for caregivers, and what keeps them coming back, in order to help improve programs for caregivers.

About Katherine… I am a PhD student in School Psychology at the University of Alberta. I like learning about what things at home and school help the social and emotional development of young kids. When I'm done school I would like to be a School Psychologist and continue to help with research. Next year I will be living in Guelph, ON and completing a School Psychology internship with the Waterloo-Region District School Board.

Research Study

Questionnaires
Interviews
Support Group & Info Sessions (Feedback forms & observations)
Questionnaires
Interviews
Feedback
Knowledge Sharing (Presentations, etc)

Participants

4 adoptive mothers, 1 grandmother, and 1 step-mother.

Purpose

To explore caregivers' experiences of participating in support group and information sessions in order to inform future programming and interventions for caregivers.

Research Design

A "community-based mixed method study" that includes information from interviews, feedback forms, observations, and questionnaires.

Research Questions

What are caregivers' experiences of participating in the psychoeducational support group & how are these experiences related to caregivers' levels of stress, sense of competence, support, & quality of life?

- Individual experiences?
- **Benefits** & barriers?
- Levels of stress, sense of competence, support, & quality of life?
- Similarities & differences across experiences?

Next steps for the research project… We will write up more about your experiences of the group and present at academic conferences (e.g., Alberta FASD Conference).

Thank you to all the caregivers that shared their time & participated in this study!

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Preliminary Results

Question: What are the aspects of the support group are reported by caregivers' to be benefits?

Sense of Community

"I am not alone"

"It helps reduce [stress] just because it gives you that venue to talk. And to hear other people's stories and just know you're not alone. That just helps so much."

"It makes you feel like you're not alone." "We're all in this together."

Normalizing experiences

"It's calming just to hear other people. Like, 'Oh my god, my kid is not the only is not that does that.' You know? The first time I went there it was the best feeling. I was like, 'Oh my god, I thought that it was just my child that does these things!'"

Understanding, Nonjudgmental attitudes & Emotional Support

"You know, really, just going and talking to these other people that are experiencing a lot of the same things. It was just even nice to know that's there. And there is a place that I can go and talk about and people understand."

"It's great outlet. It's just so great to go and hear other people talk about the same things and to get ideas, just to be with like minded people that aren't going to judge, cause you're all in the same boat. You all get it, and you don't have to worry about people with these preconceived notions about FASD. It's just good place."

"I can go there, I can shed a tear, nobody turns and laughs at you. They understand or they want to understand what you're going through, and they try to help you. They'll bring in the outside sources and that kind of helps too."

"A sounding board" & helping others

"You can voice your opinion and we're going to listen...It's like a sounding board that can help you with your daily living, like daily issues that come up."

The importance of humour

"It's nice to like go somewhere where you can say something and people aren't like 'Oh, yeah you got a problem'. And you can kind of laugh about it... Like you say something and everyone's just like 'Yeah, that's right. It sounds about right.' You can't really get that anywhere else."

Feelings of Hope: Hearing People's Stories

"I just love hearing about those stories...because that just gives me so much hope."

"It provided insight into our future...it was nice to see the future not as a big unknown, but as something manageable."

Learning about FASD

Reframing behaviour

"After the last support group I tried to see [my child] differently and not think that he's not 'wanting' to do something, and instead he 'can't' remember to do the activities. The group helps me see the good in him."

Strategies

"I love hearing other people's stories and suggestions and successes."

"It gives you guidance."

Resources & information

"The parent support group has been an awesome resource."

Self Care

"It's a break." "Really helped me relax"

Helpful Time & Place

"I do like where they have it, in that house."

"I think much more it would start to get a little crazy busy. Parents have so much stuff on the go. I think once a month is probably good."

Suggestions for Info. Sessions

- School system & how to help your child learn
- Diagnosis, health clinic information, & alternative therapies
- How to prepare your child for adult life
- FASD 101 or 201

Also: Fun days with the kids or kid get-togethers

Resources

- **Edmonton Fetal Alcohol Network (EFAN) has info on resources, programs, & services in the Edmonton area: www.edmontonfetalalcoholnetwork.org**
- **FASD Support & Resources in Alberta has a list of services and resources specifically for families: www.fasd.typepad.com**
- **The Government of Alberta FASD Cross Ministry Committee has many webcasts on topics like FASD 101, transition parenting, FASD and conduct disorder, & neuroplasticity: www.fasd-cmc.alberta.ca/education-training**

Contact Katherine Roger at the SED Lab (780-492-5624) or kroger@ualberta.ca

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Appendix R: Example of a Journal Reflection Entry

The following is an example of a journal reflection entry for a meeting with community-based research and evaluation (CBRE) partners with the *Coaching Families* program.

Meeting with CBRE Partners (Denise D, Denise P, and Sharon)
October 31, 2011

Overview

Overall, went well. Went through abstract, and they asked questions (a) the inclusion of biological fathers, (b) evaluate the support group that is already happening, rather than starting another group (c) timing, (d) learning specifically why support groups are helpful for parents.

Learned several elements: (a) most of the families are Denise's family, (b) most families have decreased stress when they are leaving the Coaching Families program, (c) believe that the support group may be helpful for the connections the make, normalizing the their experiences, and realizing they are not alone. Sharon asked whether we could ask if parents are more stressed the more diagnoses their children have.

Following the meeting, we began to email back in forth about questions they had.

Reflections:

There were several different approaches that I tried to use at the meeting today to help form a more collaborative relationship with Denise D, Denise P, and Sharon. As suggested by Sherry Ann, I suggested we make a collaborative agenda that we work through during the meeting. Although they didn't suggest any agenda items, I feel they might have appreciated the gesture, and it may have also helped to understand the collaborative nature of CBRE.

We discussed the abstract that I brought that reflects what I have been thinking about for the project over the last 8 to 10 months. They brought up specific points that they were concerned with and added areas that they felt would be interesting to investigate, which was nice and helpful. They didn't appear to have any suggestions regarding the overall issue or research approach, and I'm not sure if that is because they did not feel comfortable sharing their ideas, or if they did not have any ideas or felt they could not discuss this aspect because of their ideas of research and previous experiences working in research teams.

In terms of the issue and their interest in researching psychoeducational support group, they seem that they are interested, but not necessarily overly excited. Denise Plesuk reminded me that we have meeting several times over the last year, and touched based on this particular, which reassured me that there has been collaboration, although maybe not as much on the research side of it. I guess this is where my mind has been during the last year and I shouldn't have assumed that other people would be in the same headspace or focused on developing the same skills. I did say that if I could help in any way in the research department I would be more than happy to help in any way I could. I reiterated that I wanted to hear their perspectives concerning the project, and explained where my head has been for the last 8 months.

Overall, I believed it was a very productive meeting which left my feeling that a lot was accomplished.

Appendix S: Example of a Code Memo

Code name:	Case 3 Benefit: Building each other up
Code description:	Janelle's experience of hearing stories from others, which reminds her of universality of her experience, as well as the positive outcomes sharing her own stories about her experience. This code captures the two-way mutual benefits of sharing experiences.

Code notes: Janelle describes the transformative process of talking and hearing other people's stories - good quote.
3/30/2014 6:52 PM

Janelle talks about the emotional experience she had when she first attended the group, which I don't think she expected. She enjoys hearing peoples stories - links to "once you start talking things start moving".
3/30/2014 7:01 PM

Janelle describes the transformative process of talking and hearing other people's stories - good quote.
3/30/2014 6:52 PM

I eventually coded this "Building each other up" because I feel that best described what Janelle was taking about – both her own process of hearing stories and feeling that she wasn't alone in her experience AND the joy and competence she felt when she was able to provide strategies that she thought would be helpful to someone else based on her own experiences.
4/17/2014 4:12 PM

Today I was writing the "Benefits" of the constant comparison coding for the participant #25 (Janelle). Originally, I had included several themes as subheadings for this section:

- Building Each Other Up
    - It's Humbling to Hear
    - Giving My Two Cents
- Changing Expectations
- Making Connections Without Judgment
- Open to Ideas

While writing "Making Connections Without Judgment" I realized that

there wasn't too much "meat" in this code. It largely focused on one particular relationship she had with another caregiver in the group, and that the benefits of this relationship was largely captured under "It's Humbling to Hear," which focused these benefits more broadly. "Open to Ideas" was also captured under "Building Each Other Up" because that also focused on strategies and advice that caregivers provided to one another, and alone it only focused on one particular quote.
7/16/2014 10:07 AM

Code examples:

Building each other up. I think like the support group, I think for me personally, is more like, it's like calming just to hear other people. They're like Oh my god, my kid is not the only is not that does that. You know? Like the first time I went there was the best feeling. I was like, "Oh my god, I thought that it was just my child that does these things!" (25/T2/Line905)

It's humbling to hear. When I first came, I would cry. There was a lady who came, but she only came once, and she was talking about some kids, I think she was fostering to adopting, and she started crying, and like, it's crazy because as soon as she started crying I wanted to cry.-When I first came, I would cry… It's like that feeling of overwhelmingness. You can't even describe it. You're just, 'These are the problems, there are so many problems.' But once you start talking about them, things start moving and it's not so bad anymore. These are the problems, *but* there's all these good things too." (25/T2/Line1589)

It's like a humbling feeling of like understanding and just like, when you, you know, when you say something that you would usually say to somebody else, and they're like, oh god, like you got problems. The people there, they smile you know, it's like okay, and like even like last support group, and I was talking about [C1]'s thing and you know, everybody had an idea, everybody there, you know, they're like yeah my kids do that too, you know. (25/T9/Line982)

Giving my two cents. Apart from that though, everything, I think, has been pretty good. I like the ones where there's more time to talk and like, I like listening to other people's, what they have to say. Giving my two cents somewhere. (25/T2/Line1491)

Appendix T: Overview of analyzed data files with descriptions.

	Data File	Description
1.	Pre-intervention questionnaires	- Questionnaires focused on caregiver stress, sense of competence, social support, and quality of life. - A demographic questionnaire was also included. - Information gathered by the questionnaires helped to inform pre-interview questions, and descriptive information. - Pre-intervention questionnaires were compared to post-questionnaires to help understand the impact of the psychoeducational support group on caregivers' feelings of stress, sense of competence, and quality of life. - Six pre-intervention questionnaires for each participant were available. - Eighteen pre-intervention questionnaires were available for inclusion in the multiple case study.
2.	Pre-intervention interviews	- Interviews with caregivers prior to the psychoeducational support group focused on caregivers' experiences and aspects of the psychoeducational support group that could be modified to meet caregivers' needs. - Interview questions were informed by pre-intervention questionnaires concerning feelings of stress, sense of competence, social support, and quality of life. - One pre-intervention interview was available for analysis for each participant. - Three pre-intervention interviews were available for inclusion in the multiple case study.
3.	Observations	- During sessions, the researcher recorded field notes, including the progression of the sessions, any critical incidents that occured, and important information from the caregivers. - Five field notes of sessions were available for inclusion in the multiple case study.
4.	Feedback forms	- Caregivers were asked to write feedback forms at the beginning of each psychoeducational support group sessions regarding their experiences of the psychoeducational support group, their experiences during the weeks in between sessions, and ratings of the previous support group session. - 27 feedback forms were available for analyses from the participants. - 18 feedback forms were available for the study.

5. Attendance	- Attendance of caregivers for each session were recorded to better understand caregivers' experiences and to help understand what aspects of the group were helpful.
6. Post-intervention questionnaires	- Post-intervention questionnaires focused on the same areas assessed by the pre-questionnaires (i.e., caregiver stress, sense of competence, support, and quality of life). - Information gathered by the questionnaires helped to inform interview questions and the effect of the psychoeducational support group sessions. - Post-intervention questionnaires were compared to pre-questionnaires to help determine the impact of the psychoeducational support group on caregivers' feelings of stress, sense of competence, and quality of life. - Five post-questionnaires for each participant were available.
7. Ratings of intervention components	- An additional questionnaire asked participants to rate various componenets of the group in order to determine the usefulness of each component (i.e., content areas covered, mode of presentation, etc.). - Six ratings of session components were completed by participants. - Three ratings of the sessions components were available for inclusion in the multiple case study.
8. Post-intervention interviews	- Interviews with caregivers were completed after the psychoeducational support group sessions were completed that focused on caregivers' experiences of attending the group. - Interview questions were informed by the comparison of pre- and post-intervention questionnaires. - Six post-intervention interviews were available for analysis from participants. - Three post-intervention interviews were available for inclusion in the multiple case study.
Overview	Included in the multiple case study: - 18 pre-intervention and 15 post-intervention questionnaires - Three pre-intervention and three post-intervention interviews - Running tally of caregiver attendance - Five observations of intervention sessions - 18 feedback forms - Three ratings of session components

Appendix U: Notes regarding O'Cathain's (2010) quality framework for mixed methods research.

Domains of Quality	#	Items Within Domain	Notes
Planning quality	1	Foundational element	See Chapter 2, p. 10-45
	2	Rationale transparency	See Chapter 1, p. 6: "The rationale for using this design was that a single data set was not sufficient to answer the primary mixed method research question. The qualitative data collection, analysis, and interpretation was enhanced and augmented by the collection of secondary quantitative data."
	3	Planning transparency	Paradigm: See Chapter 1, p. 6-8 Planned design: See Chapter 3, p. 48-50 Analysis: See Chapter 3, p. 76-79 Reporting: See Appendix A, which includes a Knowledge Sharing Plan
	4	Feasibility	The study was completed. Feasibility of the project was reviewed often.
Design quality	5	Design transparency	See Chapter 3, p. 48-50
	6	Design suitability	See Chapter 3, p. 48: "In this study, a qualitative strand was added to a quantitative multiple case study for the purposes of better understanding the studied phenomenon of caregivers' experiences of participating in a psychoeducational support group using a community-based research approach."
	7	Design strength	See Chapter 3, p. 80-89
	8	Design rigor	See Chapter 3, p. 80-89
Data quality	9	Data transparency	See Chapter 3, p. 60-76
	10	Data rigor/design fidelity	See Chapter 3, p. 80-89
	11	Sampling adequacy	See Chapter 3, p. 57. Sampling had to be balanced with feasibility.
	12	Analytic adequacy	See Chapter 3, p. 76-80. Analysis techniques are appropriate for each stream.

	13 Analytic integration rigor	See Chapter 3, p. 79-80. Integration strategies are provided.
Interpretive rigor	14 Interpretive transparency	See Chapter 4. Explanation of where information originated, and what inferences are based on which data collection procedures are provided.
	15 Interpretive transparency	See Chapter 5, p. 180-195. An attempt was made to ensure that inferences are consistent with the findings that they're based.
	16 Theoretical consistency	See Chapter 5, p. 195-199. Inferences on the current study are consistent with previous research and theoretical orientations.
	17 Interpretive agreement	Peer debriefer concluded similar findings.
	18 Interpretive distinctiveness	It is argued that the conclusions drawn from the current study is more credible than other conclusions.
	19 Interpretive efficacy	Inferences are drawn from both the qualitative and quantitative findings.
	20 Interpretive bias reduction	Explanations are provided regarding inconsistencies between multiple case study findings.
	21 Interpretive correspondence	Inferences correspond to the purpose of the study and research questions. Connections between research questions and findings are direct.
Inference transferability	22 Ecological transferability	Thick, rich description lends itself to naturalistic generalizations.
	23 Population transferability	Generalizations cannot be made, but naturalistic generalizations are appropriate.
	24 Temporal transferability	Naturalistic generalizations lend themselves to temporal transferability.
	25 Theoretical transferability	It is unclear whether there is transferability of findings to other methods of measuring behaviour. Further research is needed.
Report quality	26 Report availability	Unfortunately, the study report was not completed within an appropriate time

			line. Circumstances made it difficult to complete the analysis and report after data collection was completed.
	27	Reporting transparency	Key aspects of the study, including the 6 criteria of the GRAMMS, are reported.
	28	Yield	Although it was difficult to integrate both qualitative and quantitative strands at times, it is argued that the whole of the project is more valuable than the sum of its parts.
Synthesizability	29	15 quality criteria	Not applicable
Utility	30	Utility quality	It is hoped that the findings of the project will inform future interventions for caregivers of children with FASD. This cannot be evaluated until the knowledge sharing tasks are completed.