INTERTWINING TO FIT IN: A GROUNDED THEORY STUDY OF CAREGIVERS WITH SCHOOL-AGED CHILDREN WITH FASD

by

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Abstract

My study aimed to explain how caregivers of school-aged children with FASD manage their children’s schooling. Symbolic interactionism served as the guiding theoretical perspective. I used a Glaserian approach to grounded theory to develop a substantive theory: intertwining to fit in.

I collected data through interviews, participant observation, and document analysis. I completed 30 in-depth interviews and 25 hours of participant observation with children’s caregivers between February 2009 and November 2009. I used constant comparative analysis to construct my substantive theory. Intertwining to fit in is a dynamic cycle caregivers of elementary school-aged children with FASD use to resolve their main concerns, which are preventing their children from failing academically and in social interactions and preventing themselves from being regarded as “bad” parents.

To intertwine to fit in parents used two strategies, orchestrating schooling and keeping up appearances, while they were regulating the relationships with their children. Caregivers used the strategies to try to achieve academic and social success for their children and to be regarded as “good” parents. Using the strategies successfully reduced the amount of time parents spent regulating their relationships with their children and permitted children more independence. Conditions caregivers encountered, for example key workers, influenced how caregivers used the strategies and related tactics. Using the strategies resulted in caregivers encountering two critical junctures: hitting rock bottom and reaching islands of calm. When hitting rock bottom neither of the strategies were working, children were not succeeding, and caregivers were focused on regulating relationships with their children. Reaching islands of calm occurred when strategies were successful and parents could invest
more time in themselves. During critical junctures, caregivers re-engaged with the school system. Short-term outcomes associated with critical junctures affected the long-term outcomes caregivers were trying to achieve.

“Intertwining to fit in,” contributes to literature on attachment and parenting and extends explanations about caregivers’ advocacy for their children. The substantive theory has implications for school psychology practice, training, and research, as well as school personnel. The theory is also important in illuminating approaches to managing for the caregivers of school-aged children with FASD.
Preface

This thesis is submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Faculty of Graduate Studies, School Psychology. I was solely responsible for all aspects of the research project, including recruitment of participants, data collection, coding, analysis, and writing the theory. I worked under advisement of my research committee. Ethics approval for this research was issued by the Behavioural Research Ethics Board at the University of British Columbia (certificate number: H08-02873).
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List of Abbreviations and Conventions

The first six abbreviations and conventions below pertain to quotations from interviews with participants. I then provide abbreviations of terms used throughout the thesis. To make quotations more succinct or protect the identity of children, participants or third parties, I left out some words at times or used a personal pronoun instead of a first name. Some quotations were shortened for the sake of brevity. An example is provided of abbreviations used to identify interviews and documents in quotations.

… A word or a few words omitted
.... A sentence or a few sentences omitted
[   ] Insertion of a word to aid understanding of the dialogue
1.1, lines 7-12 Participant one, interview one, lines 7-12
P Participant
R Researcher

ARND Alcohol-Related Neurodevelopmental Disorder
ADHD Attention Deficit Hyperactivity Disorder
BCAAN British Columbia Autism Assessment Network
BREB Behavioural Research Ethics Board
CBC Conjoint Behavioural Consultation
CDBC Complex Developmental Behavioural Conditions
FAE Fetal Alcohol Effects
FAS Fetal Alcohol Syndrome
FASD Fetal Alcohol Spectrum Disorder
FHAN Fraser Health Assessment Network
IDEA Individuals with Disabilities Education Act
<table>
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<td>IEP</td>
<td>Individual Education Plan</td>
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<tr>
<td>IOM</td>
<td>Institute of Medicine</td>
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<tr>
<td>LEIC</td>
<td>Learner Environment Instruction Curriculum</td>
</tr>
<tr>
<td>MLA</td>
<td>Member elected to the British Columbia Legislative Assembly</td>
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<tr>
<td>PHSA</td>
<td>Provincial Health Services Authority</td>
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<tr>
<td>POPFASD</td>
<td>Provincial Outreach Program for Fetal Alcohol Spectrum Disorder</td>
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<tr>
<td>SEA</td>
<td>Special Education Assistant</td>
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With love and appreciation,

to

Annemie Marna (Heyns) Martin (1 April, 1944-26 March, 1994)

Cornelius Frederick Martin (18 November, 1945-26 March, 1992)

my parents,

who left too early, but are with me, always
Chapter 1: Introduction

1.1 Background

Fetal alcohol spectrum disorder (FASD) is considered to be the most common form of preventable birth disorder in the western world (Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Currently, practitioners and researchers in North America use the term FASD to describe a range of physical, mental, behavioural, and/or learning disabilities that may result from prenatal exposure to alcohol (Bertrand et al., 2004). Based on the harmonization of the Institute of Medicine (IOM) criteria (Stratton, Howe, & Battaglia, 1996) and 4-Digit Diagnostic Code approaches to assess alcohol exposure, through facial anomalies, growth impairment, and brain damage (Astley & Clarren, 2000), experts in Canada developed the Canadian guidelines for diagnosis of FASD (Chudley et al., 2005). According to these guidelines, the umbrella term FASD includes the medical diagnoses of Fetal Alcohol Syndrome (FAS), Partial FAS, and Alcohol-Related Neurodevelopmental Disorder (ARND).

While the complex and interrelated features of FASD originate with organic brain damage, individuals affected by FASD vary significantly in the manner in which organic brain damage from alcohol interacts with genetic influences and environmental variables (Chudley et al., 2005). Some individuals who are prenatally exposed to alcohol experience difficulties when the primary disability interacts with external factors after birth. These acquired difficulties, also called secondary disabilities (Streissguth, Barr, Kogan, & Bookstein, 1997), include mental health problems (Burd, Martsolf, Klug, & Kerbeshian, 2003; Famy, Streissguth, & Unis, 1998; Grant, Huggins, Connor, & Streissguth, 2005;
O’Connor et al., 2002b; O’Malley & Storoz, 2003), disrupted school experience (Duquette & Stodel, 2005; Green, 2007), trouble with the law, prison confinement, inappropriate sexual behaviour (Streissguth et al., 1997), substance abuse (Baer, Sampson, Barr, Connor, & Streissguth, 2003; Famy, Streissguth, & Unis, 1998; Streissguth et al. 2004), difficulty with employment (Spohr, Willms, & Steinhausen, 2007; Streisguth et al., 1997), and difficulty with independent living (Streissguth et al., 1997, 2004).

Notwithstanding students’ experiences of learning problems, academic failure, and school drop-out (Streissguth et al., 1997), some children do persist with schooling and graduate (Duquette & Stodel, 2005; Duquette, Stodel, Fullarton, & Hagglund, 2006, 2007). Researchers have found that the development of secondary disabilities associated with FASD can be prevented or mitigated by protective factors such as early and accurate diagnosis (Astley & Clarren, 1999; Astley, Bailey, Talbot, & Clarren, 2000; Streissguth, et al., 1997), timely access to appropriate interventions and supports (Streissguth et al., 1997), living in stable home environments, (Duquette et al., 2006; Streissguth et al., 1997) and the presence of adults who can act as advocates to guarantee a supportive school environment (Streissguth, 1997; Duquette et al., 2006). In the absence of individual protective factors, such as strong academic skills, good social problem-solving skills, and high self-esteem, many students affected by FASD may be especially dependent on caregivers and school and community environments to buffer or mediate their risk factors (Duquette et al., 2006; Matsen, 1994).

In Canada, legislation, educational policies, and educational procedures vary significantly from province to province. The educational policy framework in British Columbia provides a significant role for parents in decision-making and direct involvement
in their children’s education (Province of British Columbia, 1995, 2011). Although the literature on parental involvement indicates that the connection between parental involvement and achievement is complex and not always agreed upon (Fan & Chen, 2001), a significant body of literature (e.g., Christenson, Rounds, & Gorney, 1992; Epstein, 1989, 1991, 2001) documents the benefits of parental involvement on students’ academic and social development. In an attempt to create an educational context in British Columbia where students with special needs are able to equally and meaningfully participate, the Province of British Columbia has outlined several policies, procedures, and guidelines that support the delivery of special education. Reflecting the changing values of society regarding support for children with special needs and their families, special education policies emphasize the vital role played by caregivers in the education of their children by working in partnership with educators and other service personnel.

The translation of policies and guidelines into practical support for children with special educational needs varies from one context to another. In British Columbia, new programs (Province of British Columbia, 2007) have been implemented to support students with FASD and their families. The programs are also intended to build capacity in school districts for students with FASD and their teachers. Given the dearth of studies involving children with FASD and their caregivers in the British Columbian educational context, it is unclear how educational policies affect school settings within which children with FASD and caregivers interact and how new programs might affect caregivers’ efforts to manage schooling.
1.2 Significance

In Canada, where FASD is recognized as the leading cause of developmental disability among children, the disorder is flagged as a pressing public health, education, economic, and social problem. Approximately 9 out of every 1,000 children born in Canada are estimated to be affected by FASD (Health Canada, 2005). While exact prevalence rates are difficult to determine, the publication of Canadian guidelines for diagnosing FASD (Chudley et al., 2005) and an increase in awareness of the more common, but less visible subtypes of FASD, are expected to lead to more accurate estimates of prevalence rates and incidence (O’Malley, 2007).

The direct costs associated with this life-long disability have been estimated to be about $1.5 million to $2 million per person over a lifetime; however, the loss of human potential to affected individuals and emotional costs to their caregivers are immeasurable (Health Canada, 2005; Stade, Ungar, Stevens, Beyen, & Koren, 2007). Primary and secondary disabilities associated with FASD present a wide variety of challenges for children with FASD, their caregivers, and professionals who engage with children and their families. For caregivers and professionals, the affected children’s difficulties with memory, language, communication, cooperative play, transitions, and behaviour (Harwood & Kleinfeld, 2002; Premji, Serrett, Benzies, & Hayden, 2004) present particular challenges. How these challenges affect caregivers’ behaviour in response to the experience of children with FASD in the school system is of particular interest in my study.

Despite the recognition of caregivers as important partners in the educational context through educational policies and research, studies to date have only involved caregivers of
children with FASD as recipients of educational information (e.g., Chasnoff & Rudisill, 2003; Kable, Coles, & Taddeo, 2007) or as co-recipients of interventions (e.g., Frankel, Paley, Marquart, & O’Connor, 2006; Gurwitch, Mulvihill, & Chaffin, 2003, 2006).

Qualitative studies involving caregivers of students with FASD (e.g., Duquette & Stodel, 2005; Duquette et al., 2006, 2007, Ryan & Ferguson, 2006a, 2006b) have described caregivers as being actively involved in their children’s schooling and strongly advocating for their children in the face of limited support. Unfortunately, existing studies have focused mostly on experiences of foster and adoptive parents of adolescent students. Anecdotal data and clinical wisdom emphasize early elementary school and the move to middle school as two important “turning points” in the life trajectories of students with FASD and of parents trying to help their children negotiate those turning points (Olson, Oti, Gelo, & Beck, 2009). I have located no studies that examine caregivers’ perspectives about how they manage the schooling of school-aged children with FASD. Conceptualizing data grounded in the world of caregivers of school-aged children with FASD and ordering it into a body of theory provides a way to explain caregiver behaviours in response to the experience of children with FASD in the school system.

Sandelowski (1993) argued that the task for scholars in practice-oriented disciplines is to find ways to apprehend and represent phenomena so that knowledge can be advanced and practice influenced. Indeed, intentional practice needs a strong theory base (Glaser, 1978). A substantive theory that explains how caregivers manage their children’s schooling could contribute to theory development and research, have significance for caregivers of children with FASD, and have practice implications for the fields of school psychology and education and human service professions. Capturing caregivers’ perspectives and alerting
educators and school administrators about the conditions that influence caregiver behaviour could contribute to improvements in collaboration between schools and caregivers of children with FASD.

1.3 Purpose and Aims

The purpose of my study is to develop a substantive theory about how primary caregivers of elementary school-aged children with FASD in British Columbia manage their children’s schooling. My aims are to explain: how caregivers of elementary school-aged children act as they try to manage their children’s schooling; contextual factors that affect caregivers’ efforts to manage their children’s schooling; and effects of contextual factors on primary caregivers’ efforts to manage their children’s schooling. Contextual factors in this study are conceptualized as micro- to macro-level conditions that influence caregivers and their children.

Because the nature of the purpose and aims of the study involve explanation, I judged a qualitative design to be most appropriate. Specifically, I chose grounded theory as a strategy of inquiry because my intent was to generate substantive theory, grounded in data generated from caregivers of school-aged children with FASD. I aimed for the theory to conceptualize and explain how caregivers continuously processed their main concerns.

1.4 Theoretical Basis of the Study

As a major theoretical perspective informing the study, symbolic interactionism, as defined by Mead (1934), Blumer (1969), and Perinbanayagam (1985), offers theoretical
propositions linked to self, social interactions, and symbols that can guide a study examining how caregivers manage their children’s schooling when the children are affected by FASD.

1.5 Background of the Investigator

Hall, Long, Bermbach, Jordan, and Patterson (2005) argued that background experiences, associated with disciplinary education and training, sensitize the researcher to form guidelines and reference points to formulate questions and concepts. Background experiences influence the “many selves” that researchers bring to the research situation, which can also affect the interpretation of data. Acknowledging the educational and training experiences I bring to the research situation forms part of an attempt to manage my subjectivities (Morrow, 2005) when acting as the main instrument during the research process.

I registered as a clinical psychologist at the Master’s level, following completion of a M.A. degree in Clinical Psychology at a university in Johannesburg, South Africa. My training took place within a framework that sensitized me to the influence of wider systemic factors on behaviour. Rotations in community and hospital settings inspired me to undertake further studies to enhance my knowledge of behaviour of exceptional children. The clinical experiences also sensitized me to the behaviour of caregivers of children with mental health problems and other difficulties.

Following my move to Canada, from 1997 to 2002, I worked as a family and children’s therapist in the mental health context in Vancouver. During that time, I obtained valuable experience working with exceptional children, including children with FASD.
Through my immersion in the mental health context, I became interested in how mental health issues may impact learning.

In 2005, I started my Ph.D. program in School Psychology at the University of British Columbia. My interest in the impact of childhood disorders on caregiver behaviours developed from my experiences as a mental health therapist and school psychology practicum student. Volunteer assessment experiences and exposure to the FASD literature, through academic coursework and practicum experiences, further developed my interest in the substantive area of FASD.

Following completion of coursework and comprehensive exams, I finished my internship in a school district in the Lower Mainland of British Columbia. My internship experiences sensitized me to how educational policies influence the educational context in which caregivers interact.

1.6 Organization of the Thesis

In this introductory chapter, I provided background information, addressed the significance of the study, summarized the purpose and aims, and briefly introduced the theoretical basis for the study. I concluded with a short description of my background. This section serves to orient the reader to the organization of the thesis. In Chapter 2, I synthesize the literature to provide the context and to demonstrate the need for the proposed study. In Chapter 3, I discuss the theoretical perspective I used to inform the study and the methodological implications that flow from the underlying theoretical perspective. While methodology embraces the whole scientific quest and covers the principles that guide the generation of knowledge (Blumer, 1969), method refers to the procedures by which the
theory is developed. In Chapter 4, I explicate the research method used for the study while attending to the methodological issues that were raised in Chapter 3. I describe the study design and provide definitions for my research terms. I list the research questions and describe ethical considerations, data collection procedures, theoretical sampling, data analysis and theoretical memos, and rigour. In Chapter 5, I describe the sample characteristics to provide a context for the findings and to orient the reader to the nature of the sample. Following an overview of the theory, I describe the core category that was developed and the categories that are related to the core category. I discuss the findings in Chapter 6, where I compare my developed theory with extant theories and the research literature. I discuss the limitations of the research study and the implications for school psychologists, educators and key workers, and conclude with a description of the significance of the theory for caregivers.
Chapter 2: Review of the Literature

2.1 Introduction

The place of the literature review in qualitative research is an issue of considerable debate among researchers. The controversy extends to grounded theory research. As pointed out by Cutcliffe (2000) and Heath (2006), some researchers (e.g., Hutchinson, 1993; Strauss & Corbin, 1990) advocate for a literature review before collecting data, to justify and situate the study; others (e.g., Glaser, 1978, 1992; Stern, 1994) argue that a literature search prior to data collection and analysis should be avoided altogether. According to Glaser, whatever literature is necessary to place findings in context will become known as the theory is developed. The extant literature will be incorporated into the developing theory as one more piece of data. Cutcliffe proposed that the differing positions for the place of the literature review are not necessarily contradictory, but represent different positions on the continuum of knowledge generation. Researchers who perform the literature review before beginning data collection and analysis take the position that the most appropriate methodology will be indicated by the state of the knowledge regarding the phenomenon. According to Cutcliffe, researchers who avoid conducting a literature review prior to commencing data collection and analysis (e.g., Lincoln & Guba, 1985; Stern, 1994) claim that they have recognized the dearth of knowledge concerning the phenomenon and have, therefore, decided that a grounded theory approach would be suitable.

Glaser, who describes grounded theory as a “general inductive method possessed by no discipline, theoretical perspective, or data type” (Glaser, 2005, p. 141) acts as a
spokesperson for researchers in grounded theory who strongly believe that avoiding a literature review in the area of interest at the beginning of the study increases the likelihood that the emergent theory will be grounded in data. According to Glaser (1998):

The first step in grounded theory is to enter the substantive field for research, without knowing the problem. This requires suspending your knowledge, especially of the literature, and your experience. The researcher must take a “no preconceived interest” approach and not ask questions that might be on his mind (p. 122).

While Glaser’s position on trust in the emergence of concepts during data analysis is clear, it would be problematic for me to use for my study for two reasons. First, Glaser’s (1992) stance, while consistent with the positivistic underpinnings of grounded theory, presupposes the neutrality of the researcher. Glaser has expressed concern that researchers can contaminate theory development with pre-conceived ideas that may not really fit the data, work, or be relevant. Alternatively, Suddaby (2006) purported that contamination of the researcher’s perspective is less of a concern than is the danger of prior knowledge leading to hypothesis testing. “either overtly or unconsciously” (p. 635). Glaser’s stance on the neutrality of the researcher has been challenged by other grounded theory researchers (e.g., Charmaz, 2000, 2006; Strauss & Corbin, 1990) and, as I describe in the next chapter, is not consistent with the ontological and epistemological underpinnings of my study. The second reason is that academic rigour requires a traditional literature review. A review of the literature contributes to meeting requirements of research ethics committees (Strauss & Corbin, 1998), supporting the significance of the study, and indicating whether grounded theory is an appropriate method for funding purposes (McGhee, Marland, & Atkinson, 2007).
Students adhering to principles of classical grounded theory, while satisfying academic demands, often navigate these issues by occupying a position of middle ground (see for example, Mordoch, 2005). This position seems to be supported by the literature. For example, Fassinger (2005) gravitated to the middle ground by recommending researchers possess minimal familiarity with the literature in the early stages of conceptualizing the study. Fassinger claimed that

the researcher must strike a delicate balance between enough knowledge to focus the sampling and data collection effectively and yet not so much immersion in existing perspectives that the investigation becomes circumscribed by preordained constructs and limited expectations (p.158).

To avoid relying on preconceived concepts and derailing the theory, as mentioned by Glaser (1978), but to satisfy academic requirements, I adopted a middle ground position for the initial literature review in this study. In doing so, I also started to address the tension between the original positivistic underpinnings of grounded theory and my own position. I regard reality is a social construction and have been sensitized by previous clinical and educational experiences. Thus, it is impossible for me to enter the research process tabula rasa. I further discuss these methodological dilemmas in Chapter 3. Therefore, the purpose of this chapter is to provide a context for the proposed study, demonstrate the need for the proposed study, critically evaluate studies that bear significantly on the topic, and provide the rationale for conducting the study.

In the first section, I discuss the primary and secondary disabilities associated with prenatal exposure to alcohol. In the next section, I describe challenges related to the
prevention of secondary disabilities, with reference to obtaining a diagnosis and receiving support, as well as challenges related to the caregiving environment. I follow that description with ways in which these challenges are addressed in the British Columbian context. In the final section, I present a critical analysis and synthesis of studies describing the experiences of caregivers in interactions with the school system to demonstrate the need for the study. Given that this study took place in British Columbia, I make reference to the educational landscape of this province where applicable.

2.2 Primary and Secondary Disabilities

School-aged children with FASD have primary and secondary disabilities that affect their day-to-day functioning in school. Streissguth (1997) defined primary disabilities as the disabilities a child is born with, which reflect the central nervous system dysfunctions inherent in the FAS or FAE diagnosis; secondary disabilities were defined as those that arise after birth and presumably could be ameliorated through better understanding of children’s conditions and appropriate interventions.

Primary disabilities caused by alcohol damage to developing brain cells include vision and hearing problems (Burd, Cotsonas-Hassler, Martsof, & Kerbeshian, 2003); scoliosis, epilepsy, urinary tract infections, and congenital heart problems (Becker, War-Leeper, & Leeper, 1990; Church & Kaltenbach, 1997); and fine and gross motor problems (Barr, Streissguth, Darby, & Sampson, 1990). Other difficulties that affect children’s abilities to function in school include memory problems (Kerns, Don, Mateer, & Streissguth, 1997), speech and language disorders (Timler, Olswang, & Coggins, 2005), problems with adaptive functioning (Jirikovic, Olson, & Kartin, 2008), and behavioural challenges (Burgess &
Streissguth, 1990; Nanson & Hisock, 1990; Streissguth et al., 1996). Common behaviours noted in school-aged children include difficulties with communication, transitions, cooperative play, and behaviour modulation (Harwood & Kleinfeld, 2002; Premji, Serrett, Benzies, & Hayden, 2004). According to Streissguth (1997), the basic cognitive, attention, and memory problems experienced by students set the stage for behaviour problems in the classroom and at home, because students repeatedly fail to meet expectations. Over time, patterns of defensive behaviours (i.e., secondary disabilities) develop, which are believed to be preventable with appropriate supports (Malbin, 2002; Streissguth, Barr, Kogan, & Bookstein, 1996).

An important four-year study on secondary disabilities and risk and protective factors (Streissguth et al., 1997) provided empirical evidence suggesting the population of individuals with FAS and FAE are at heightened risk for disrupted schooling. They used a life history interview with parents and caregivers of 415 individuals with FAS (33%) and FAE (67%) to identify secondary disabilities, such as mental health problems (90%), trouble with the law (60%), inappropriate sexual behaviour or involvement in sexual offender treatment programs (49%), and substance abuse or confinement in a mental health treatment program (50%). Specifically, in their study, 60% of the subjects who were 12 years and older, and 14% of the subjects who were under age 12 experienced interruptions to their learning processes. The authors noted that suspensions were the most often reported interruptions, with inattention and incomplete work accounting for the most frequent learning problems across all ages. The most frequent behaviour problems included being disruptive in class and not getting along with peers.
In an evaluative report of the British Columbia Key Worker and Support Program (a program established to provide assistance to caregivers and service providers associated with children with FASD), Hume et al. (2008) indicated that caregivers in British Columbia perceived their children to experience a variety of secondary behaviours that were both school-related and of a social/emotional nature. Frustration was the most frequent school-related secondary behaviour, involving 73% of the children seeking key worker services. Children’s social-emotional secondary behaviours that were most frequently identified by caregivers included anger problems, behaviour problems, and anxiety.

In the absence of individual protective factors, such as strong academic skills, good social problem-solving skills, and high self-esteem, many students affected by FASD may be especially dependent on family, school, and community environments to buffer or mediate their risk factors (Duquette et al., 2006; Matsen, 1994) and to prevent secondary disabilities from developing. As purported by Giunta and Streissguth (1988), families of children with FASD “assume a responsibility far beyond that normally associated with parenting” (p.458). The challenges to the prevention of secondary disabilities will be discussed in the next section.

2.3 Challenges Related to the Prevention of Secondary Disabilities

Challenges associated with the prevention of secondary disabilities relate to the process of diagnosis, the delivery of school-based supports, and caregiving environments. Illuminating these challenges is important because they affect the school-based experiences of students with FASD and, as documented in descriptive studies situated outside British
Columbia (e.g., Duquette & Stodel, 2005; Duquette et al., 2006, 2007; Ryan & Ferguson, 2006a, 2006b), appear to affect the experiences of their caregivers.

### 2.3.1 Challenges Related to the Process of Diagnosis

The complicated profiles and unpredictable behaviours of many children with FASD present unique challenges to those who support them in schools. First, educators and support personnel have to try to understand how the brain of each student affected by FASD responds and how each student can be best supported. Turner (2006) argued that a contributing factor to the challenge is that many children prenatally exposed to alcohol are not diagnosed before school entry or school personnel may be unaware of previous assessment results.

Not only are manifestations of the disturbances caused by prenatal alcohol exposure unique to each individual (Malbin, 1993), but also developmental disturbances associated with different stages of development, (i.e., preschool, elementary school, and adolescence) vary and may not be attributed to FASD (Graefe, 1998; Harwood & Kleinfeld, 2002). In addition, most school-based psycho-educational assessments are intended to focus on learning strengths and weaknesses and may not reveal some of the neurological deficits associated with prenatal exposure to alcohol (Blackburn, Carpenter, & Egerton, 2010; Connor, Sampson, Bookstein, Barr, & Streissguth, 2001; Steinhausen, Willms, & Spohr, 1993). Significant cognitive deficits in memory, attention, and executive functioning, which are not consistently captured with overall cognitive scores, can affect the ability of children with FASD to function in school (Kodituwakku, 2007; Streissguth, 1997). How children’s difficulties in functioning in school affect their caregivers’ behavioural responses has not been systematically documented in the FASD literature.
A third difficulty identified by Green (2007) is that more specialized (neurological) testing, which is necessary to document deficits in executive functioning (i.e., planning, organization, and attention), may not always be available. Children who have deficits that are undiagnosed or unrecognized may not qualify for the needed supports within the education system. In the absence of diagnosis or identification of a child with FASD, caregivers may not be able to access appropriate services and support (Clarren, Olson, Clarren, & Astley, 2000; Streissguth & Giunta, 1988). Early diagnosis and access to appropriate services are important protective factors identified by Streissguth et al. (1996) in their life history interviews with parents and caregivers of patients 12 years and older.

Although appropriate supports and interventions can ameliorate or prevent secondary disabilities associated with prenatal exposure to alcohol, children require early recognition of their disorders. According to Chudley et al. (2005), Canadian guidelines for diagnosis can present a number of challenges regarding the diagnosis of FASD. First, identifying the conditions on the FASD spectrum requires complete histories and physical exams, as well as neurobehavioural assessments. Chudley and colleagues argued that a lack of available evidence and data in key areas (e.g., Canadian growth norms) limits the effectiveness of the diagnostic process. Second, because treatment planning and implementation should be targeted towards the unique needs of the individual and family, a multidisciplinary team approach is essential. Chudley et al. suggested that a limited capacity, even in some large communities in Canada, exists for providing a multidisciplinary team-based approach.

While screening should not be equated with diagnosis, Chudley and colleagues (2005) noted that, in some communities with no diagnostic services, screening tools have been used inappropriately in lieu of a proper diagnosis. In addition, Coles (2003) expressed
concern that the majority of children on the FASD spectrum do not meet the criteria for a formal diagnosis and, as a result, do not qualify for services and supports. Their inability to qualify occurs despite demonstrating cognitive, social, emotional, and behavioural difficulties associated with the teratogenic effects of alcohol on the brain. The author’s claim is consistent with the findings of Streissguth et al. (1997) that a diagnosis of FAS, rather than FAE, is a protective factor. Given the deficits associated with prenatal exposure to alcohol and the complexities of diagnosis and support, it is important to seek caregivers’ perspectives about managing their children’s schooling.

2.3.2 Challenges Related to the Delivery of School-Based Supports

In addition to difficulties with obtaining a diagnosis, a second barrier identified in the literature pertains to the “assessment-intervention” gap. Ryan and Ferguson (2006a) conducted a three-year qualitative study investigating the process of diagnosis and the experiences of professionals and families associated with four boys and one girl with FASD living in five areas across Alaska. The authors emphasized the need for coordinated services for students with FASD and supports for their families, based on their findings of (a) pervasive effects of children’s difficult behaviours, in the context of limited supports; (b) use of differentiated instruction by experienced teachers but not by beginning teachers; and (c) increased public awareness of FASD, with limited provision of services for children with FASD and their families. In light of their evidence, they suggested that obtaining a diagnosis did not always lead to support for children and their families. The authors identified a need to coordinate services between diagnosis and intervention, with the identification of the family’s support needs as an important study implication.
A major difference between the educational landscape in Alaska at the time of Ryan and Ferguson’s (2006a) study and the current landscape in British Columbia is the fact that FAS and FASD were not eligible categories for support in Alaska. Streissguth (1997) pointed out that students with FASD may sometimes be diagnosed with disorders, such as autism, that could potentially lead to supports in school. On the other hand, Ryan and Ferguson concluded that most students with an unrecognized FASD “fall between the cracks” (p. 376). The students may not receive the critical supports and services to avoid problematic outcomes such as school suspensions and expulsions. The FASD scholarly literature has failed to address the question of how caregivers respond to lack of supports for children. It is also not clear how the existence of eligibility criteria for support influence both children and their caregivers.

2.3.3 Challenges Related to the Caregiving Environment

A third challenge is related to caregiving environments. Researchers have increasingly moved toward an ecological approach for understanding the factors that contribute to child development (e.g., Bronfenbrenner, 1977, 1979, 1986, 1992; Garbarino, 1990). The complex interaction between individual and environmental factors is particularly evident when attempting to understand the dynamics of prenatal exposure to alcohol and children’s development. Caregiving environments for children with FASD contribute to our understanding of the effects of prenatal exposure to alcohol on the outcomes for children. Duquette et al. (2006) and Matsen (1994) pointed out that many students affected by FASD are especially dependent on caregiving environments to provide buffers that reduce their risk
factors because of the lack of individual protective factors such as strong academic skills, good social problem-solving skills, and high self-esteem.

Of the eight universal protective factors identified by Streissguth et al. (1997, 2004), most are related to being raised in a stable and nurturing environment; specifically, living with nurturing parents in a stable and well-resourced home environment for more than 72% of a child’s life. While all children benefit from a stable and nurturing home environment, children with FASD can particularly benefit because the experience can prevent the development of secondary disabilities. Coggins, Timler, and Olswang (2007) concluded that children with FASD, “perhaps more than any other clinical population, live in an extended state of double jeopardy due to the timing, quantity and pattern of maternal drinking and the frequently co-occurring adverse effects of dysfunctional caregiving” (p. 125).

Children with FASD, may experience caregiving environments characterized by the continued use of alcohol and/or other substances and/or the presence of physical or emotional abuse; those exposures create more immediate risks. Streissguth et al. (2004) found that 67% of the 415 subjects (aged 6 to 51 years) with FAS/FAE reported experiencing either physical or sexual abuse and/or domestic violence. Zuckerman (1991) reported that children who are raised in families abusing alcohol and other substances are more likely to grow up in environments characterized by social isolation, poor coping skills, and problems with accessing community resources. The increased risk for neurobiological, psychophysiological, and/or psychological deficits for children living in violent and/or impoverished environments is well documented in the literature (e.g., Cicchetti, 2004; Kaufman, Plotsky, Nemeroff, & Charney, 2000).
Substance abuse, in combination with factors such as poverty, is more likely to result in mothers giving birth to a child with FASD. Poverty and substance abuse together increase children’s risks that exposure to alcohol will be expressed as significant deficits (Rasmussen et al., 2008) and that they would eventually be entering foster care (Stukes Chipungu, & Bent-Goodley, 2004). Children with FASD are over-represented in foster care (Besinger, Garland, Litrownik, & Landsverk, 1999). Following entry to care, the environment of children can continue being unstable. The stability of the out-of-home caregiving environment of children with FASD is affected by the challenging nature of raising a child with FASD in the context of a lack of support and barriers to accessing support (Hume et al., 2008; Olson et al., 2009).

Giunta and Streissguth (1988) noted that caregivers of children with FASD “assume a responsibility far beyond that normally associated with parenting” (p. 458). Nevertheless, as indicated by a Canadian report on guidelines for families caring for children with FASD (Victoria Order of Nurses, 2006), the need for respite care for caregivers is a critical area that has not been adequately addressed in Canada. A recent evaluation of the British Columbia Key Worker and Support Program concluded that caregivers of children with FASD continue to experience unmet needs for respite care, which contribute to placement breakdown (Hume et al., 2008).

In one study, 63 licensed foster parents in a central Canadian province confirmed they would consider ending a placement if they did not receive respite care (Brown, Bednar, & Sigvaldason, 2007). The foster parents described feeling taken for granted, having insufficient information about the children, or caring for children with serious behaviour problems. When the living environments are unstable or characterized by frequent changes
secondary disabilities become more evident and children’s school functioning may be influenced.

Problems in accessing community resources may create additional hurdles for biological families raising children with FASD. Hume et al. (2008) noted that biological parents and grandparents have a unique set of support needs. Similarly to Legge, Robberts, and Butler (2000), Hume and colleagues reported birth parents’ fear of being judged by other members of support groups (e.g., adoptive and foster parents), which led to their hesitation to seek support. In particular, for families from smaller communities, the stigma associated with FASD presents a particular challenge, which affects their willingness to seek help (Alberta Centre for Child, Family and Community Research, 2009).

Grandparents who are raising children with FASD experience additional barriers. Although only 1% of children in Canada live with their grandparents, 17% of the participants across British Columbia who accessed the Key Worker and Parent Support program were grandparents. Canadian research studies (Fuller-Thompson, 2005) have found that grandparent-headed households are disproportionately female (59%), Aboriginal (17%), external to the labour force (57%), and living in poverty (>30%).

In addition to financial hardships experienced by many grandparents who are taking care of children with FASD, grandparents may not feel comfortable accessing support groups because, in addition to the fear of stigma, they feel out of place with a younger parenting group (Hume et al., 2008). When caregivers are hesitant to access support because they feel out of place or are fearful of being judged, they may not receive the type of help that can contribute to the children’s success in school.
The literature provides no insight about how access to support services influences the caregivers’ attempts to manage their children’s schooling or how accessing services might contribute to success. Moreover, potential influences of stigma and the fear of being labeled on caregivers’ actions have not been systematically documented. Studies that determine effects of influences on caregivers’ behaviours and caregivers’ perceptions about environments for successful outcomes are important to advance the agenda to support children with FASD.

2.4 Addressing Challenges Related to the Prevention of Secondary Disabilities in British Columbia

As described in the previous section, challenges associated with the prevention of secondary disabilities include the process of diagnosis, the delivery of school-based supports, and caregiving environments. By exacerbating primary disabilities resulting from the damage to brain cells due to maternal alcohol consumption, systemic barriers and environmental factors enhance negative developmental consequences by the time children enter school. Lack of appropriate supports (in schools and homes) compound the negative developmental consequences for many children with FASD leading to an increase in stress for caregivers and a greater potential for placement breakdown.

In British Columbia, the educational landscape has been changing with regards to service delivery for children with FASD and their families. In September, 2006, the British Columbian Ministry of Education committed funding to establish a new FASD provincial outreach program, the Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD). The program shares research evidence and resources with teachers, parents,
students, and others to build capacity in school districts for students with FASD and their teachers. In addition, the formation of recent partnerships between the Provincial Health Services Authority (PHSA), the British Columbia Autism Assessment Network (BCAAN), and the Fraser Health Assessment Network (FHAN) for Complex Developmental Behavioural Conditions (CDBC) is intended to provide timely assessment and diagnosis for children who live in the Fraser Health area of British Columbia and are suspected of having FASD or other complex developmental behavioural conditions (Province of British Columbia, 2007).

As indicated by Special Education guidelines in British Columbia, students who are diagnosed through the CDBC Network may receive extensive support and intervention in schools. Students’ reception of support requires clinical diagnostic assessment by a qualified specialist with information integrated from multiple sources and various professionals from different disciplines (Province of British Columbia, 1995, 2011). The clinical diagnostic assessment is a time-consuming process that depends on interdisciplinary collaboration. Systemic barriers to this process in the British Columbian context include finding physicians that will refer families for the assessment, as well as waiting times for assessments (Hume, Rutman, Hubberstey, & Johnson, 2007; Province of British Columbia, 2007). The contributions associated with availability of support programs, assessment networks, and special education guidelines to success for caregivers and children have not been studied. Moreover, against the backdrop of the changing educational environment, exploration of caregivers’ perspectives on what is important for success would be particularly timely.

The current educational environment in British Columbia includes specific eligibility categories for children with FASD. In the British Columbian education system the need for
special education services is predicated on a student having been designated with physical
disability or chronic health impairment due to: (a) a nervous system impairment that has an
impact on movement or mobility, (b) musculoskeletal conditions, and/or (c) chronic health
impairments that seriously affect the student’s education and achievement. Students who are
diagnosed through the appropriate network, such as children and youth with complex needs,
may be included in the category “Physical Disabilities or Chronic Health Conditions,” if their
functioning in school is significantly affected by their conditions. Students with FASD may
receive interventions and support at school if they are included in the category (Province of

The purpose of special education in British Columbia is to enable the equitable
participation of students with special needs in the educational system; therefore, problems
and concerns around the educational functioning of children with special needs should
(ideally) be addressed through a process of collaborative consultation. According to
educational policies (Province of British Columbia; 1995, 2011), a successful collaborative
process has the following features:

It is voluntary; there is mutual trust and open communication among the people
involved; identification/clarification of the problem to be addressed is a shared task;
the goal is shared by all participants; each participant’s contribution is valued equally;
all participants’ skills are employed in identifying and selecting problem-solving
strategies; and there is shared responsibility for the program or strategy initiated (p. v).
The process of consultation assumes that all participants (parents, teachers, and other professionals) have a responsibility to work together in the best interest of students. The importance of a collaborative relationship between schools and caregivers of children with FASD has been anecdotally reported since the mid-1970s by parents, teachers, and clinicians working with children prenatally exposed to alcohol. Nonetheless, studies to date have not systematically explained how caregivers of school-aged children navigate multilayered consultative social situations.

The ability of children with FASD to follow instructions and behave appropriately varies from day-to-day and across settings (Burgess, 1994; Burgess & Streissguth, 1990) and, according to Timler and Olswang (2001), inconsistency in behaviour affects the perceptions of caregivers and teachers with regards to the types of educational supports needed to facilitate optimal performance. As argued by Streissguth (1997), the different perceptions of teachers and parents about children with FASD often results in disagreement about the best way to support the children, leading to less effective service provision. Collaboration between teachers and caregivers will be affected by factors such as different perceptions and trust (Blue-Banning et al., 2004).

Missing from the current body of literature about FASD is knowledge about how caregivers of elementary school students with FASD construct their realities as they interact with schools, interpret and assign meaning to their experiences, and base their actions on assigned meanings. Capturing caregivers’ perspectives and explaining how they manage could be an important step in improving the collaboration between schools and caregivers. A few limited reports (e.g., Hume et al., 2008) indicate that factors, such as fear of stigma or being judged, affect parents’ efforts to seek support. Open communication and trust with
schools may be problematic for biological parents of students with FASD because of the stigma associated with drinking during pregnancy. What is less clear is how factors such as stigma might affect the caregivers’ interactions with, and perceptions of, educational environments.

In addition to systemic challenges, the nature of the caregiving environment presents challenges for many families raising children with FASD. Such challenges can include the secondary disabilities associated with FASD (Brown, Bednar, & Sigvaldason, 2007); lack of support or barriers to accessing support (Hume et al., 2008; Olson et al., 2009); limited resources (Payley, O’Connor, Frankel, & Marquardt, 2006); and, for some families, challenges related to the continued use of alcohol and/or other substances and/or the presence of physical or emotional abuse (Fagerlund, Autti-Ramo, Hoyme, Mattson, & Korkman, 2011; Streissguth et al., 2004).

Olson et al. (2009) reviewed informal literature and a small body of systematic studies of FASD and caregiver function and concluded that a positive and stable family environment for school-aged children is not the norm. They pointed out that conduct problems raise questions for caregivers about causes of their children’s behaviour and what constitutes reasonable expectations. After reviewing anecdotal data and clinical wisdom captured in the informal literature, the authors suggested that early elementary school and the move to middle school present important “turning points” in the life trajectories of students with FASD and of parents trying to negotiate the turning points. Recognizing the challenges associated with raising a child with FASD, the Province of British Columbia recently introduced new approaches to provide assistance to families of children and youth with FASD and similar conditions. Two support programs introduced in most communities in
British Columbia during the latter half of 2006 were the Key Worker Program and Parent Support (Province of British Columbia, 2007).

Key workers support caregivers, family members, and service providers to identify ways to adapt children’s environments in response to their needs. They strive to create conditions for families to become the best advocates for their children and to provide parents with information about supports that may be available in or near their communities. Parent support includes local parent and grandparent FASD training, parent mentoring, and parent support groups (Province of British Columbia, 2007). Because there is a dearth of studies involving caregivers of children with FASD in British Columbia it is unclear whether or not access to support programs affects caregivers’ behaviour or their interactions with their children’s school environments. In an attempt to address the dearth of research involving students and parents in the educational context, researchers have conducted studies that describe the experiences of mostly adolescent students with FASD and their foster and adoptive parents. I will discuss these studies in the next section.

2.5 Caregiver Experience in Interactions with the School System

There has been a focus in the FASD literature on incidence (e.g., Habbick, Nanson, Snydre, Casey, & Schulman, 1996; Robinson, Conry & Conry, 1987) and diagnosis of FASD (e.g., Astley & Clarren 1999, 2000; Godel et al., 2000), IQ scores of children with FASD (e.g., Burgess & Streissguth, 1990; Steinhausen, Willms, & Spohr, 1993), and characteristics of children with FASD (e.g., Dufour, Williams, Campbell, & Aitken, 1994); few studies have involved caregivers of children with FASD in the educational context.
My review of the literature indicates that the caregivers of students with FASD involved in intervention studies rated their children’s behaviour (e.g., Johnson & Lapadat, 2000) or were recipients of interventions (e.g., Chasnoff & Rudisill, 2003; Frankel, Paley, Marquart, & O’Connor, 2006; Gurwitch, Mulvihill & Chaffin, 2003, 2006; Kable, Coles, & Taddeo, 2007). Clark, Hughes, and Jaswal (2010) reviewed the FASD intervention literature and concluded that intervention studies to date have been focused on improving children’s behaviour, school performance, social skills, and executive functioning. The studies have not focused on perspectives and behaviours of caregivers. The extant research leaves a gap in understanding how caregivers of children with FASD interact with school systems.

I identified studies about caregivers that were conducted by researchers in the United States and Eastern Canada (e.g., Duquette & Stodel, 2005; Duquette et al., 2006, 2007, Ryan & Ferguson, 2006a, 2006b); those studies described the experiences of both students with FASD and their caregivers. Using an adapted grounded theory approach (Strauss & Corbin, 1998), Duquette and Stodel (2005) explored the educational experiences of seven adopted children/adolescents/young adults (aged 9 to 28 years), from the perspective of the adoptees and their 11 adoptive parents. Three of the young adult participants provided a retrospective view of their school experiences. Data were collected through questionnaires, which consisted of open-ended items, and semi-structured interviews. Some researchers (see for example, Tan & Hall, 2007) point out that, only through interactions among researchers and participants in naturalistic settings, can local and shared constructions of reality be drawn out, refined, interpreted, and compared. Questionnaires do not provide the kind of access to local and shared constructions of reality equivalent to in-depth interviewing in naturalistic settings. Parents were asked to describe the process of obtaining a diagnosis, the services
their children received in school, the nature of their children’s inclusion in schools, the elements of a successful school experience, and their concerns and aspirations for their children. The study findings suggest that all of the children experienced problems in the areas of reading and math and, consistent with the findings of Streissguth et al. (1996), the children had either occasional or long-standing behaviour problems.

Duquette and Stodel (2005) attended to trustworthiness of the findings through triangulation and member checks; however, a study limitation included the retrospective nature of some of the interview data. Furthermore, they indicated that all of the participants were “middle class adoptive parents from the cultural majority,” (p. 57) who advocated for their children and provided a stable home environment. While birth parent status has been associated with higher parenting role-related stress (Paley et al., 2006), there is a paucity of data about the experiences of birth parents in interactions with the school system.

Duquette and Stodel’s (2005) study contributes to the FASD literature in two ways. First, it defined a “successful school experience” from the perspective of individuals with FASD and their adoptive parents, specifically academic achievement, obtaining a high school diploma, and social inclusion. Second, their findings highlighted four elements contributing to a successful school experience for children with FASD: (a) accurate diagnoses; (b) appropriate programs and services (i.e., the availability of specialized programs as required and the assignment of a paraprofessional, if required); (c) caring teachers (i.e., teachers who are knowledgeable about FASD, prepared to work with parents, and willing to make accommodations); and (d) parents advocating for their children and providing ongoing support.
In two follow-up studies, Duquette et al. (2006, 2007) attempted to understand the educational experiences of adolescents who persisted in high school and graduated. The participants in the studies included eight adolescents ranging in age from 15 to 20 years, and 16 adoptive parents who resided in either Canada or the United States. The researchers used a collective case study method and a phenomenological conceptual framework. Two conditions emerged from the data that strongly contributed to persistence: social interaction; and strong and unwavering advocacy and support from caregivers. The findings extend existing work from Duquette and Stodel (2005), which indicated the importance of parental advocacy for ensuring a successful school experience for children with FASD.

Studies of children and their caregivers indicate that the necessary support from the school and community is not consistently forthcoming and students persist mainly due to strong advocacy from their adoptive parents. The literature on FASD (e.g., Streissguth, et al., 1996, 1997) also points to a stable home environment and the presence of an adult advocate as protective factors against secondary disabilities. The findings add to Murray’s (2003) research by including advocacy as an important protective family characteristic and a protective factor that mediates the risks associated with FASD (Duquette & Orders, 2010; Duquette et al., 2006). Linking protective factors to positive educational outcomes extends Streissguth et al.’s (1996, 1997) work. Nonetheless, studies have only provided descriptions of the adoptive parents as strong advocates for their children who are actively involved in their children’s schooling. To address the gap in the FASD literature, study designs need to include more caregiver types (e.g., biological parents, foster parents and grandparents), capture the perspectives of caregivers of school-aged children, and move beyond description
of caregiver experiences to conceptualizing and explaining their behaviours and the conditions that influence their behaviours.

Ryan and Ferguson (2006a) conducted a three-year qualitative study to investigate the process of diagnosis of FASD and the experiences of professionals and families. Their study sample included four boys and one girl (aged 3 to 19 years) with FASD, living in five areas across Alaska. Their study revealed similar themes to earlier studies but added the voices of biological parents, extended family members, parent advocates (in this context, parents who support a family through the diagnostic process), teachers, and other professionals involved with the children with FASD. They completed over 135 interviews with 71 participants.

Consistent with other studies (Duquette & Stodel, 2005; Duquette et al., 2006, 2007), Ryan and Ferguson (2006a) indicated that families were frustrated and overwhelmed by the challenging behaviours of their children. They were also frustrated by the absence of community and school-based services and/or lack of consistent or sufficient services. Ryan and Ferguson noted that persistent attempts were made by parents to find sufficient services for their children and the consequences of such persistence for parents’ emotional well-being. Ryan and Ferguson raised several unanswered questions: namely, what factors did the families think contributed to the lack of provision of services and supports; what supports did families identify as helpful; and why did the families not receive the supports? Furthermore, their findings were situated in the Alaskan context when FASD was not an eligibility category under the U.S. Individuals with Disabilities Education Act (IDEA). Educational policies (which are based on the ideological values of society) guide teachers and other school professionals, influence the governance of school boards, and affect the settings where children and caregivers interact. How educational policies in British Columbia affect the
settings where caregivers and children interact has not been addressed in the FASD literature. Indeed, accessing the perspectives of caregivers with children attending schools in British Columbia would be crucial to determine how potentially helpful policies might affect the children’s success.

An unpublished evaluation of a pilot project in British Columbia explored experiences of students with FASD and their parents, in interactions with the British Columbian school and support systems (Shepard, Guenette, & Crawford, 2005). The project, which involved interdisciplinary assessment and a support project for 15 students (aged 7 to 15 years) with suspected FASD, was implemented to provide timely diagnosis, assessment, and planning for children. To assess the effectiveness of the diagnosis and assessment process, the researchers evaluated caregivers’ levels of satisfaction with services, their needs and concerns, and support they received while participating in the project.

The foster parents in Shepard et al.’s (2005) study indicated that they struggled to persuade educators and school administrators to understand their children’s learning and behavioural needs. They actively advocated for their children. The authors reported the explanatory and affirming value of receiving a diagnosis for some participants (but not all) and emphasized the need for school supports. Some parents expressed their concerns about the process of diagnosis, which could lead to further exclusion rather than concrete services for their children. Parents were apprehensive about obtaining adequate support, especially when their children moved to high school. Shepard et al.’s results are consistent with studies conducted by Duquette and colleagues (Duquette & Stodel, 2005; Duquette et al., 2006, 2007).
The report by Shepard et al. (2005) documented caregivers’ struggles and fear of stigma, which potentially prevented caregivers from engaging in actions that could lead to help for their children in the school system. The research results did not explain factors that affect children’s success and effects on caregivers’ behaviours. The report adds the voices of British Columbian caregivers to the literature; however, the results do not address caregivers’ approaches to these situations and effects of factors, such as fear of exclusion for their children.

2.6 Summary

I have indicated the necessity for a literature review and critically evaluated only those studies that bear significantly on the topic and provide the rationale for conducting this study. I have discussed primary and secondary disabilities associated with FASD and summarized challenges related to the prevention of secondary disabilities. I have summarized how challenges have been addressed in British Columbia, followed by my analysis and synthesis of qualitative studies describing caregiver experiences in interactions with the school system.

School-aged children with FASD have primary and secondary disabilities that significantly affect their day-to-day functioning in school. Challenges exist with regard to the prevention of secondary disabilities, specifically, for the process of diagnosis, delivery of school-based supports, and for the caregiving environment. While special education policies for the support of children with FASD exist, effects of such policies in the British Columbian educational context have not been addressed. Some factors, such as fear of judgment or fear of their children being labeled, seem to prevent caregivers from accessing the kind of help
needed by their children to succeed. Most studies on caregiver experiences have explored the educational experiences of small numbers of individuals with FASD from the perspectives of the individuals and their adoptive parents or other family members and professionals (Duquette & Stodel, 2005; Duquette et al., 2006, 2007; Ryan & Ferguson, 2006a, 2006b). The studies have identified elements that contribute to a successful school experience. Findings across studies indicate that support from schools is often absent or inconsistent and that caregivers need to persistently and strongly advocate for appropriate programs and services (Duquette & Stodel, 2005; Duquette et al., 2006, 2007; Ryan & Ferguson, 2006a, 2006b). I concluded the chapter by synthesizing qualitative studies of caregiver experiences in interactions with the school system. These studies showed that caregivers have been actively involved in their children’s schooling and strong advocates for their children in the face of limited support. Most studies have accessed adoptive parents of adolescent students. No studies have examined the caregivers’ perspectives about how they manage the schooling of their child with FASD. The FASD literature has failed in systematically addressing how children’s difficulties in functioning in school affect the behaviour of their caregivers, what care providers think is important about their environments for successful outcomes, and how educational policies and factors such as stigma might affect caregivers’ interactions with and perceptions of educational environments. There are gaps in our understanding about how caregivers navigate multilayered social situations or make sense of things, as they act and interact within the school systems, or how the school system affects the caregivers’ efforts to manage their children’s schooling. Focusing on the perspectives of multiple types of caregivers for school-aged children with FASD and explaining their behaviours would add to the literature. I have identified the gaps in the literature which underline the importance of
accessing the perspectives of caregivers who have school-aged children attending schools in British Columbia.

In Chapter 3 (Theoretical Perspective), I will provide an overview of the theoretical perspective that has informed my study and justify my processes underlying the research choices I have made and actions I have taken. I will begin with the theoretical perspective that guides the study, followed by the use of grounded theory as a method, and finish with the criteria for rigour.
Chapter 3: Theoretical Perspective

3.1 Introduction

To address the issue of quality in qualitative research, scholars/authors propose critically examining descriptions of ontology, epistemology, and methodology (Lincoln & Guba, 1985) and demonstrating the fit between theoretical perspectives, methodology, method, and research questions (Crotty, 1998; Edwards & Titchen, 2003). Moreover, Tan and Hall (2007) call for “purposefully leveraging” (p. 589) the respective strengths of an informing theoretical perspective and chosen strategy of inquiry. Using this background, my purpose in this chapter is to discuss the theoretical perspective I used to inform my study and to justify the process behind the research choices I made. My reflexivity about the theoretical perspective that guided the study process is important because research questions, data collection, and data analysis are influenced by the theoretical perspective.

In the first section of this chapter, I describe the main theoretical perspective that informed the study: symbolic interactionism. While interpretations of symbolic interactionism are numerous (Reynolds, 1993) and discussion of various interpretations is beyond the scope of this chapter, I argue that symbolic interactionism, as defined by Mead (1934), Blumer (1969), and Perinbanayagam (1985), offers theoretical propositions that can effectively guide a study examining how caregivers manage their children’s schooling when the children are affected by FASD. I discuss concepts from symbolic interactionism, which I regard as being central to the study. I also discuss the strengths, limitations, and ontological
and epistemological underpinnings of symbolic interactionism. I conclude the section with a summary of the methodological implications of symbolic interactionism.

In the second section, I describe the methodological implications that follow from the main theoretical perspective. In “adopting a position of intense methodological awareness” (Seale, 1999, p. 3), I explain the framing of the overall research question; justify the use of grounded theory as a strategy of inquiry, including how I navigated between Glaser’s (1978, 1992, 1998) and Strauss and Corbin’s (1990) approaches to data analysis; pay attention to how “leveraging” the guiding theory and the strategy of inquiry can enhance the quality of the study; and finally, argue for taking up criteria for rigour in addition to those identified by Glaser (Crotty, 1998; Hall & Callery, 2001; Higgs & Titchen, 1998).

3.2 Symbolic Interactionism

Symbolic interactionism is an interpretive theoretical perspective (Reynolds, 1993). In linking the concepts of mind, self, and society, Blumer (1969), who coined the term “symbolic interactionism,” developed Mead’s (1934) ideas into a theoretical perspective, which sought to explain human behaviour in terms of meaning derived from interaction with significant others. Blumer’s (1969) definition of “symbolic interaction” is as follows:

The term refers, of course, to the peculiar and distinctive character of interaction as it takes place between human beings. The peculiarity consists in the fact that human beings interpret or “define” each other’s actions instead of merely reacting to each other’s actions. Their “response” is not made directly to the actions of one another but instead is based on the meaning which they attach to such actions. Thus, human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the
meaning of one another’s actions. This mediation is equivalent to inserting a process of interpretation between stimulus and response in the case of human behaviour (p. 78-79).

The premises of symbolic interactionism, as defined by Blumer (1969), are that human beings act towards things on the basis of the meanings that the things have for them; meaning arises from social interactions between people; and meanings of things are modified through an interpretive process as humans deal with things they encounter. Concepts contained in these premises are important to the current study and are explored further in the next section.

3.2.1 Concepts

The concepts underlying symbolic interactionism that I regard as central to the study are: the self, objects, symbols, the act, social interaction, and societies. I describe the concepts in the following sub-sections.

3.2.1.1 The Self

Mead (1934) articulated the origins and actions of the self. In Mead’s view, human society is composed of individuals who have “selves”. The self is constantly emerging and is defined and redefined by interactions with significant others. As emphasized by Blumer (1969), Mead viewed the self as process. During interactions with others, humans incorporate the definitions made by others through the process of role-taking. In Mead’s view, the process of role-taking makes human society possible. As humans learn and use symbols
(mostly spoken language) and develop meanings for objects in their environments, they develop a mind that is both reflecting and reflexive, or acting toward itself.

Mead (1934) emphasized the human capacity for having perspective on oneself. In communicating with the self, humans become the object of their own actions (Reynolds, 1990). According to Blumer (1969), the self is the mechanism that facilitates internal (interactions with self) and external (interactions with others) conversations. Perinbanayagam (1985) extended Blumer’s idea of the self, by purporting the self exists only as a facet of interaction or dialogic acts. Self and communication, according to Peribanayagam, are intertwined in that communication cannot happen apart from the presence of selves and selves find their possibility and existence in dialogic acts, or conversations.

Mead (1934) argued that two components of the self are acting together, the I and the me, allowing for both dialectical and reflexive processes. As pointed out by Perinbanayagam, Mead’s I and me have been referred to as the subjective and objective aspects of the self. The I is the part of the self that spontaneously responds, while the me is that part of the self that represents the expectations and meanings of the group. Blumer (1969) described self-interactions as a process of making indications. Mead’s concepts of the self and self-indications are important in that they allow for internal reflection prior to acting. Consider the following “self-interaction” from a participant in the current study:

I need support for my daughter… she’s going to learn… she’s going to have a heck of a time, I’m thinking to myself… but not look at it as a negative thing but as a positive thing, so that I can learn as well and learn with her… yeah… so that’s how it worked out to be (1.1, lines 482-486).
In this case, self-interaction served as a mechanism for directing a caregiver’s future action to initiate assessment for her daughter. Symbolic interactionism’s focus on the self, specifically, its allowance for internal reflection prior to acting (Blumer, 1969), has implications at the methodological level for this study. Edwards and Titchen (2003) proposed that inner conversations or reflections may be the vehicle by which participants organize their experiences, in the case of this study, how caregivers manage their children’s schooling. The self emerges from, and to some extent, reflects the larger social structure, but simultaneously creates and changes that same structure. Blumer (1969) argued that people’s actions produce the very structures within which their activities take place.

3.2.1.2 Objects

According to Blumer (1969), the “worlds” that exist for human beings and their groups are composed of physical objects (e.g., plastic container), social objects (e.g., students, caregivers, or behaviours) and abstract objects (e.g., educational policies or individual education plans). An object is anything that can be referred to and exist as a product of symbolic interaction. Objects do not have inherent meaning. Instead, the nature of an object consists of the meaning it has for a person. An object may therefore have different meanings for different individuals. Consider the different meanings two caregivers assign to the individualized education plan for their children:

[It is] a very, very focused meeting… the focus on the strength first and foremost and then it focuses on weaknesses… they do their best to help out my recognizing the weakness and try and resolve it and how to make it better for them (2.1, lines 450-452), and
The IEP is another thing that you’re supposed to… as a parent, you’re asked to sign them and they become a legal document and they become… your signature becomes… in my view… an approval of what they’re going to do (4.1, lines 97-100).

While caregivers may symbolically subscribe to the same shared notions of the individual education plan at a broader level, local meanings can differ and depend on interactions in a given situation.

3.2.1.3 Symbols

As mentioned before, the notion of symbols underpins Blumer’s (1969) premises. Symbols, as referred to by interactionists, are primarily spoken language (Tan & Hall, 2007) but can also include non-verbal communication.

A central focus for symbolic interactionism is the acquisition and generation of meaning. Meanings are acquired and negotiated through continuing interpretative processes of everyday social interactions, modified through interpretation, and communicated to others through symbols. Meaning, as defined by interactionists, must be recognized as changing over time. The researcher is, therefore, required to investigate shifts and trajectories of experience and the influences that affect perceptions and identities of participants (Kearney, Murphy, & Rosenbaum, 1994).

3.2.1.4 The Act

Perinbanayagam (1985), in reviewing Mead’s stages of the act, concluded that human life consists of a series of acts, the product of which is meaning. Perinbanayagam introduced the term “dialogic acts” to conceptualize human acts. Acts are characterized by communication and language. Blumer (1969) argued that action is constructed from what
individuals take into account as they try to cope with the world. Group action, in Blumer’s view, can be defined as the fitting together of lines of action through role-taking. By making indications to themselves and by interpreting what is indicated, people forge together lines of action. To act, an individual has to set goals, map out lines of behaviour, interpret the actions of others, and continuously assess situations.

Perinbanayagam (1985) suggested that humans exist in a framework of time and, unlike other animals, are conscious of the temporal process. The temporal order has been culturally devised and is available as concrete and culturally defined units (e.g., the school year). Acts are fulfilled in full awareness of the temporal process and its sequences. Temporal reality is acknowledged and maintained by members of the group to which each person belongs and becomes “an essential feature of social acts as well as of self, consciousness, and discourse” (p. 8).

3.2.1.5 Social Interaction

Mead (1934) saw social interaction as the crux of society. Blumer (1969), who referred to Mead’s social act as “joined action,” focused on society as a process and as socially constructing reality. Social interaction can be non-symbolic, where human beings respond directly to one another’s gestures, or symbolic, where actions are founded on the basis of the meaning yielded by interpretation (Blumer, 1969). People are constantly involved in interpretive interaction. Symbolic interactionists emphasize that individuals share one another’s behaviour, rather than merely respond to one another’s behaviour (Reynolds, 1993). Interaction itself is the unit of study. In Perinbanayagam’s (1985) view, the interaction
of a person with at least one other person in the construction of “stable meanings, relationships and worlds” (p. 3) forms the social act.

Social acts are often characterized by the presence of problematic events (Perinbanayagam, 1985). People engage in social acts to confront and overcome problems and to do this, they use strategies and invest effort, creativity, and interest. Perinbanayagam argued that, rather than developing individual acts in relation to problems, people often routinize their acts, leading to a schedule of activities that make up the everyday lives of people. While other people, customs, or traditions can exercise control over these schedules, people can also adjust these schedules.

3.2.1.6 Societies

From Mead’s (1934) vantage point, human behaviour unfolds in the association of actors with one another and is explained through consideration of the collectivities of which actors are a part. Mead (1934) viewed “society” as individuals in interaction and in association with each other. Society is established dynamically and interactively. Blumer (1969) defined human society as “people meeting their conditions in life” (p. 74). Because meanings that form society can be changed and individuals can change the myriad of meanings that form their society, society is a social product (Reynolds, 1990). Symbolic interactionism minimizes the notion that structural features limit society being formed as a social product. Actors are able to form conceptions of the perspectives held by others. They can take each other’s point of view and guide their behaviour to fit the lines of action of others (Mead, 1934). Reference groups are those whose perspectives are shared by individuals. The basis of group life, as seen by Mead, is the ability of actors to take the role
and attitude of others. For example, the caregivers in the proposed study may or may not have reference groups that include other caregivers of children with FASD, other parents at their children’s schools, or members of support groups they attend. From Mead’s discussion of society, symbols, and role-taking (even for caregivers who isolate themselves from society by excluding caregivers of children with FASD as a reference group), society, and the group are ever-present. Caregivers carry with them the mental images of the groups and society in which they dwell (Reynolds, 1993).

### 3.2.2 Strengths of Symbolic Interactionism

Tan and Hall (2007) argued that an enumeration of symbolic interactionism by Reynolds (1990) best captures its theoretical strengths: reality is understood as a social production; interaction is symbolic; humans have the capacity to engage in self-reflexive behaviour; the group is an important factor in shaping and motivating behaviour; society is as ongoing process; and social and physical environments set limits, but do not determine behaviour (p. 593).

The theoretical propositions, captured by Reynolds’ enumeration of symbolic interactionism’s strengths, show potential for guiding a study that examines how caregivers of children with FASD manage their children’s schooling. At the heart of the interactionist perspective is the issue of personal agency, which refers to the ability of people to construct and influence social reality and shape their social worlds (Sandstrom & Fine, 2003). Symbolic interactionism places the participants in my study as agents who, rather than merely responding to what plays from “outside, inside or both,” interpret what confronts them and organize their actions based on those interpretations (Blumer, 1969, p. 62). Even
when activities are limited by constraints of social institutions, such as schools, actors can still have a “modicum of autonomy” (Perinbanayagam, 1985, p. 53). They can choose to withhold action, inspect, judge, determine possibilities, and direct their action (Blumer, 1969).

Because symbolic interactionism highlights the idiosyncratic, personal, and social construction of the meaning of experience (Edwards & Titchen, 2003), it has much potential to guide a study examining caregivers’ perspectives. The theory also emphasizes the need to examine human interactions (Blumer, 1998; Mead, 1934), which lends itself to a study of caregivers’ behaviours as they manage their children’s schooling. The theory provides this researcher with a way to understand how caregivers manage their children’s schooling in terms of how they act, how they make sense of their own and others’ actions, and how they are motivated by their perceptions. Furthermore, the theory facilitates my insights into the ongoing process of social life as it is lived by caregivers over time and on a daily basis during social interactions.

3.2.3 Limitations of Symbolic Interactionism

Limitations to symbolic interactionism have been raised by “insiders” such as Meltzer and Denzin (as cited by Reynolds, 1993) including: a lack of conceptual clarity; no detailing of strategies to assess and measure interaction processes; an overemphasis on meaning at the cost of attention to social structure; a failure to address the political system sufficiently; a lack of attention to the positive adaptive aspects of a “fragmented set” (p. 130) of multiple identities; and minimization of the effect of biological factors on behaviour.
“Outsiders,” such as Reynolds and Reynolds (1973) concurred that symbolic interactionism manifests an astructural bias and is bound to be ahistorical and apolitical (Reynolds, 1993). It fails to connect face-to-face accounts with structural contexts, producing an idealistic picture of social reality. In other words, attention to social and historical conditions and the role of macro phenomena, such as the role of power on interactions and the way power can inhibit marginal groups from voicing their realities, is lacking (Hall, 1998; Kushner & Morrow, 2003; Stryker, 1987).

Social structure is not well defined in the symbolic interactionist literature despite its close relationship with agency and importance in examining social interaction (Nairn, 2009). According to Nairn, social structure is “patterns of behaviour that re-occur” (p. 2). Applying Nairn’s line of reasoning to the current study, teacher-caregiver interactions might be better understood from understanding the structural location of “teacher” and “caregiver.” This location influences the way interactions take place, in the context of broader social, economic, and historical factors. Caregivers’ behaviours and their understanding of their circumstances are affected by structural factors.

With regard to the criticism that symbolic interactionism is unable to adequately conceptualize macro phenomena, such as the role of power and its influence on interactions, Brown (2004) pointed out that this potential weakness has to do with how symbolic interactionism is practiced, rather than with the theory itself. Reynolds (1993) concluded that textual material dealing with macrosociological matters has merely been overlooked. Hall (1987), for example, contested the view that symbolic interactionism does not attend to macro-level realities in his review of interactionist scholarship. Hall presented a set of analytical categories (e.g., collective activity, network, conventions-practices, resources,
processuality-temporality, and grounding) as a paradigm for studying social organization. He focused on the meso domain, where situated activity, history, and structure converge. Dennis and Martin (2005) also refuted the criticism that symbolic interactionism ignores power by pointing out the literature on deviance and education, which focuses on the way power relations are enacted and sustained and how they contribute to the structuring of societies.

While macro-level realities have been partially addressed, symbolic interactionism appears to be limited in terms of its attention to social structure, especially when compared to functionalists or critical theorists (Maines, 1977). Symbolic interactionists “emphasize social process rather than social structure as the imagery appropriate to the study of ongoing human group life” (Lal, 1995, p. 423). A focus on the microsystem of interactions makes the wider context in which interactions take place, less of a concern for symbolic interactionists. In a study investigating caregivers’ management of their children’s schooling, the wider context and the potential effects of cultural belief systems in terms of supporting children with FASD in schools may be important.

I discuss the ontological and epistemological underpinnings of symbolic interactionism next. Foregrounding these assumptions is important because they have methodological implications for my study.

### 3.2.4 Ontological and Epistemological Underpinnings of Symbolic Interactionism

Lincoln and Guba (1985) referred to ontology as the form and nature of reality and what can be known about it and epistemology as the nature of the relationship between the knower and what can be known.
The ontological position of symbolic interactionism is that an objective reality exists; however, multiple locally-constructed understandings of reality or meanings can emerge out of day-to-day interactions (Tan & Hall, 2007). Reality is consequently understood as a social production (Reynolds, 1990). Symbolic interactionism could therefore be positioned between the postpositivist stance, with its acknowledgement of an objective reality that is only apprehended and measured imperfectly (Lincoln & Guba, 2000) and the constructivist stance, with its adherence to a relativist position that assumes multiple, apprehensible, and equally valid realities (Schwandt, 1994). At the epistemological level, symbolic interactionism is positioned closest to constructionism, with its acceptance of human beings as active constructors of meaning (W.A. Hall, personal communication, October 5, 2007). Symbolic interactionists view the investigator and object of investigation as interactively linked and co-creators of the findings during the investigative process (Tan & Hall, 2007). Understanding is co-created, and reality is understood through and with people and text. The process of communication, especially language, enables shared understanding to take place, which is how symbolization occurs.

3.2.5 Summary of Methodological Implications of Symbolic Interactionism

From the preceding discussion of the underlying premises and ontological and epistemological underpinnings of symbolic interactionism, my methodological position that follows is fourfold: First, because symbolic interactionism acknowledges personal agency and respect for the actor and the implications of a point of view, the focus on my investigation will be on understanding how caregivers interpret and judge the actions of self and others, by employing methods that captured the participants’ points of view and enable
them to speak for themselves (Lal, 1995). Because symbolic interactionists hold that the researcher needs to explicate the process by which meaning is developed and the nature of meanings that are represented in interactions between or among human beings (Schwandt, 1994) and meanings need to be understood, my data should be collected through in-depth interviews, which allow me to question meaning and increase my understanding of implicit and explicit meanings. In-depth interviews provide the space to learn about the decisions participants make about actions, the meanings they attribute to their actions, and the interpretations they make of their own, and of others’ actions (Lal, 1995).

Second, using symbolic interaction as a theoretical framework places emphasis on discovering what is going on in the substantive area being studied, by “(lifting) the veils that obscure … what is going on… by getting close to the area (of group life) one proposes to study” (Blumer, 1969, p. 39); points of resistance can be recognized in observations (Blumer, 1969). Only through interactions among the researcher and participants in naturalistic settings, can the local and shared constructions of reality be drawn out, refined, interpreted, and compared (Tan & Hall, 2007). Seaman (2008) indicated that “comparing observational data with interview data, for example, can reveal the extent to which respondents individually identify with or abandon the conceptual or material artifacts used publicly in collective situations” (p. 12). The reason for this is that researchers can observe behaviour rather than just having it described in interviews. In other words, methodologically, participant observation is useful in observing behaviour in response to lines of action of others.

Third, acknowledging the view that humans continuously adapt to an ever-changing social world, I am expected to account for process or change over time. Human group life
takes on the character of an ongoing process through the process of symbolic interaction. Through the process of definition and interpretation, lines of action are fitted together. Through constant redefinition, new objects, new relations, and new types of behaviour are formed (Blumer, 1969).

Fourth, because symbolic interactionists claim that document analysis contributes to bringing researchers in close contact with the social worlds of their participants (Blumer, 1969), I will incorporate document analysis in my study. Understanding the meaning participants make of their experience depends on understanding the context, among other factors (Morrow, 2005) and analyzing documents (e.g., educational policies) supplements the data from interviews. Blumer (1969) concluded that “human documents may be very serviceable in aiding the student to acquire an intimate acquaintance with the kind of experience he is studying, in suggesting leads, in enabling insight, and in helping him to frame more fruitful questions” (p. 125). In a study revolving around the substantive areas of FASD and caregiver-school interactions, sources of imagery available to caregivers through institutions, such as the school, the mass media, and popular culture, may be important since they can “influence the process of collective definition and the construction of action” (Lal, 1995, p. 425).

3.3 Further Methodological Implications of the Theoretical Perspective: Research Questions, Strategy of Inquiry, and Rigour

In this section, I continue to address the methodological implications that follow from using symbolic interactionism. I explain my framing of the overall research question, justify my use of grounded theory as a strategy of inquiry, including how I navigated between
Glaser’s (1978, 1992, 1998) and Strauss and Corbin’s (1990) approaches to data analysis; describe my view of how “leveraging” the guiding theory and the strategy of inquiry can enhance the quality of the study, and finally, argue for taking up criteria for rigour in addition to those identified by Glaser (Crotty, 1998; Hall, 1998; Higgs & Titchen, 1998).

3.3.1 Framing the Research Question

Hall et al. (2005) argued that background experiences, associated with disciplinary education and training, sensitize the researcher to form guidelines and reference points to formulate questions and concepts. While the purpose of a classical grounded theory study is to discover the main concern of the participants and how they continue to process the main concern (Glaser, 1978), in Chapter 2, I conducted a limited search of the literature to frame an overall research question: “How do caregivers of children with FASD manage their children’s schooling?” While the question acknowledges the personal agency of caregivers, and thereby accounts for using symbolic interactionism as my guiding theory, I framed it to encompass my openness to the participants’ problems and how they worked to resolve those problems (Giske & Artinian, 2007).

With regard to the use of the term “manage,” Hall (1998) argued that such a term, compared to terms such as “cope,” could help the researcher avoid “ascribing concept labels that may not be grounded in data” (p. 63). I also trusted in Glaser’s (1978) notion that, should “manage” not be relevant for phrasing my overarching research question, the “pre-idea” (p. 44) would soon be corrected by the constant comparisons and the emergence of concepts. After all, as Glaser (1978) stated, “social organization of life is always in the process of
resolving relevant problems for the participants in the action scene” (p. 45).

I entered the research situation with an assumption or “pre-idea” that contextual factors (e.g., educational policies) might affect how caregivers try to resolve their main concerns. In departing from Glaser’s (1992) stance, that the focus for the research will emerge “out of open coding, collection by theoretical sampling, and analyzing by constant comparison” (p. 25), my assumptions led to the incorporation of questions that acknowledged the possible effects of contextual factors on the caregivers’ management of their children’s schooling.

3.3.2 The Strategy of Inquiry: Grounded Theory

Grounded theory is both a general method and a product. Grounded theory, as a method, was developed by the American sociologists, Anselm Strauss and Barney Glaser (Glaser & Strauss, 1967), and further explicated by Strauss and Juliet Corbin (Strauss & Corbin, 1990) and Glaser (1978, 1992, 1998). Glaser (1998) defined grounded theory as the systematic generation of theory from data acquired by a rigorous research method. The grounded theory product is a set of conceptual hypotheses, or probability statements, about the relationships between concepts, which is intended to generate a theory that accounts for a pattern of behaviour through which participants attempt to deal with their main concerns (Glaser, 1978). The main features of the grounded theory method – theoretically sampling, using constant comparative analysis, coding and categorizing, writing memos, and generating theory – occur simultaneously throughout the research project (Glaser & Strauss, 1967; Glaser, 1978). While Glaser (2005) contested this view, grounded theory is understood by
most authors (e.g., Annells, 1996; Kools, McCarthy, Durham, & Robrecht, 1995; Suddaby, 2006) as deriving its theoretical underpinnings from pragmatism and early symbolic interactionist thought.

Grounded theory has been complicated by points of departure between Glaser and Strauss. At the centre of the Glaser-Strauss debate (Glaser, 1992), is the data analysis process. Glaser (1992) accused Strauss of creating an “almost new method… producing forced, full conceptual description” (p. 5). Criticisms in the literature, in response to Strauss and Corbin’s (1990) explication of grounded theory, include the suggestion that the version is “rather programmatic and over formulaic” (Melia, 1996, p. 370). In addition to Glaser’s departure from Strauss and Corbin, in framing the research question, Melia (1996) pointed out that Glaser’s objections also revolve around the initial coding process and because the researcher tries to verify the fit within and between categories throughout the process, the verificational nature of their model. With regard to the initial coding process, Melia juxtaposed the approaches of Strauss and Corbin and Glaser to illustrate this point of departure. According to Strauss and Corbin (1990):

Conceptualizing our data becomes the first step in analysis. By breaking down and conceptualizing we mean taking apart an observation, a sentence, a paragraph and giving each discrete incident, idea or event, a name, something that stands for …a phenomenon (p. 63).

Glaser (1992), on the other hand, stated that:

By breaking down and conceptualizing the data we do not mean taking apart a single observation, sentence, paragraph, and giving each discrete incident, idea, or event a
conceptual name, which indicates something that stands for or represents a phenomenon…It would end up in an over-conceptualization of a single incident (p. 40).

Glaser (1992), instead, wanted the researcher to:

look for patterns so that a pattern of many similar incidents can be given a conceptual name as a category, and dissimilar incidents can be given a name as a property of a category and the compared incidents can be seen as interchangeable incidents for the same concept (p. 40).

In terms of the role of verification in grounded theory, Strauss and Corbin (1994) supported the view that grounded theory research deals with verification and discovery. Annells (1996); however, pointed out that Strauss and Corbin do not use the term “verified” in the positivist or postpositivist sense, but rather, referred to the steps within the constant comparison that offer a verification throughout the research project.

In my study, I followed Glaser’s approach to data analysis (Glaser & Strauss, 1967; Glaser, 1978, 1992, 1998). I rejected Strauss and Corbin’s (1990, 1998) interactionist coding paradigm because it provided a more structured approach to data collection and analysis from its emphasis on the context, the conditions which give rise to the central phenomenon, the action/interaction strategies by which it is managed, and the consequences of those strategies. I was swayed by Glaser’s (1992) argument that using a structured model to inform the analysis of the research data may result in forcing the data. Glaser’s approach appealed to me because I was most interested in capturing the caregivers’ perceptions, instead of
preconceived ideas. On the other hand, I disagreed with Glaser’s (1978, 1992) argument that the central conceptual category would emerge from the constant comparisons that drive the coding of data. In using symbolic interactionism as a theoretical framework, the central or core conceptual category, rather than emerging from the comparisons, is developed, and the data and categories are co-constructed.

3.3.3 Leveraging Symbolic Interactionism with Grounded Theory

Grounded theory was the method of choice because it fits the aims of the study; namely, to produce an explanatory product. Furthermore, authors such as Hall (1998) and Mordoch (2005) proposed that a grounded theory approach is well suited to offset criticisms of symbolic interactionism, such as inadequate conceptual and theoretical development, astructural bias, lack of methodological rigour, and an idealistic vision of reality. Because “grounded theory requires complete development of concepts included in a substantive theory and encourages linkages of concepts to their related propositions within the theoretical coding procedure” (Mordoch, 2005, p. 84) I regarded the method as offsetting criticism of lack of conceptual and theoretical development in symbolic interactionism.

The main features of grounded theory include theoretical sampling, theoretical memos, and the method of constant comparison, all of which occur simultaneously throughout the research process (Glaser, 1978; Glaser & Strauss, 1967). Tan, Wang, and Zhu (2008) argued that the rigourous constant comparison technique from grounded theory offers a much-needed analytical edge to sharpen theoretical insights from using symbolic interactionism. Hall (1998) proposed that these procedures could also address the issues of emergent bias and lack of methodological rigour, two criticisms of symbolic interactionism.
The emergent nature of classical grounded theory (Glaser, 1992) permits macro system issues and power dynamics to earn their way in the process of theoretical sampling, open coding, and constant comparisons, if relevant to participants. The grounded theory method has its own internal criteria for judging the rigour of the grounded theory product; therefore, it offsets the criticism that symbolic interactionism lacks methodological rigour. Finally, Hall (1998) pointed out that the attention of grounded theory to structural features, such as resources and power, could address the criticism of symbolic interactionism’s idealistic vision of social reality.

Grounded theory has attracted criticism which includes a lack of clear explication of epistemological assumptions and reference to and use of existing theoretical frameworks (McCann & Clark, 2003). A fundamental criticism of Glaser’s approach to grounded theory is his tendency to treat theory as though it dwells in the data, ready to emerge. My use of symbolic interactionism as a guiding theoretical perspective addresses that criticism; my study is both planned and emergent (Bruce, 2007).

My leveraging of grounded theory with symbolic interactionism also creates tensions. Grounded theory has positivist underpinnings. Glaserian grounded theory, with its particular focus on discovery, has traditionally been aligned with objectivism, which reflects the view that things exist as meaningful entities independent of consciousness and experience and have truth and meaning residing in them as objects (Crotty, 1998). Glaser’s approach presupposes the neutrality of the researcher and the existence of objective meaning within the data. Using Glaser’s lens treats interview and observation data as reproductions of the participants’ realities, without paying attention to the effects of interactions between researchers and participants (Hall & Callery, 2001). He has not acknowledged the social
construction of the interview. Attempts by Straus and Corbin (1994) and especially Charmaz (1995), to reposition grounded theory, thereby potentially addressing these tensions, have led to criticism (e.g., Mills, Bonner, & Francis, 2006) of grounded theory as being “ontologically ambivalent.” Tan and Hall (2007) proposed that these tensions can be addressed by expanding the criteria for rigour to include reflexivity and relationality, in addition to applying criteria for rigour that is typically associated with grounded theory. The criteria for rigour will be described in the next section, and further explored in relation to the data presented in Chapter 4.

3.3.4 Rigour

To navigate considerations of rigour when using symbolic interactionism, I started from the positions of Rolfe (2006) and Tan and Hall (2007). These authors argue that the criteria for rigour have to be relevant for a particular study, consistent with the guiding theory and the epistemological foundations of the strategy of inquiry. In this section, I introduce the criteria for rigour that are used in the study. A generic form of rigour in qualitative research that I consider is auditability, which is defined as making steps in the research process clear so that another researcher can follow the audit trail or decisions made (Lincoln & Guba, 1985; Sandelowski, 1986).

I regard going beyond a general set of criteria for rigour as important to attend to the rigour of the grounded theory product. I have relied on the internal criteria for rigour explicated by Glaser (1978, 1992), including fit, work, relevance, modifiability, parsimony, and scope. I define these terms briefly. Glaser defined fit as the relationship of the core category to the salient social problem and its ability to account for most of the variation in
behaviour used to address the problem. If a grounded theory works it explains the major variations in behaviour that the subject tries to address in a meaningful way. If a grounded theory fits and works it has achieved relevance. Furthermore, a core category that fits, is relevant, and works can be modified when new data present variations in properties and categories. Accounting for as much variation in the data with as few concepts as possible maximizes parsimony and scope (Glaser, 1978, 1992).

The criteria I have outlined reflect only grounded theory’s positivistic roots, which presuppose the neutrality of the researcher (Crotty, 1998). They do not acknowledge the researcher’s contribution to the social construction of knowledge or issues around power and trust (Hall & Callery, 2001). Thus, I support the view that they are inconsistent with the epistemological underpinnings of symbolic interactionism. Because grounded theory research requires interpersonal interaction (Hutchinson, 1993) (in this study, interaction between the researcher and caregivers), the study process should account for the influence of the researcher on the construction of data. In an effort to be more consistent with the epistemological underpinnings of symbolic interactionism, I have incorporated Hall and Callery’s (2001) proposal to include two additional criteria for rigour in grounded theory: reflexivity and relationality.

Hall and Callery (2001) defined reflexivity as “attending to the effects of researcher-participant interactions on the construction of data” and relationality as “attending to power and trust relationships between researchers and participants” (p. 257). To ensure that the findings are grounded in data, as per the method of constant comparison, rather than being derived from my own preconceived framework, I intend to be reflexive throughout the research process (McGhee, Marland, & Atkinson, 2007). In addition, because power
differences have the potential to distort truth claims (Carspecken, 1996), I recognize that attending to relationality is important. Attempts to transform participants into “co-researchers,” do not always acknowledge power relationships that exist between researchers and participants because the researcher is privy to knowledge that the participant does not have (Haverkamp, 2005).

By incorporating the criteria of reflexivity and relationality in my study, I make the process of creating data within a grounded theory more transparent. As Tan and Hall (2007) argued, I ensure explicit consideration not only of the procedures by which the data are collected and analyzed but also of the impact of researcher-subject relationships during the course of the investigation. I view these criteria as addressing the influence of investigator-participant interactions on the construction of data. In other words, they account for the social construction of knowledge and co-construction of meaning (Hall & Callery, 2001).

Although theoretical sensitivity appears to be “the central underpinning to claims about reflexivity” (Hall, 1998), I suggest theoretical sensitivity deserves special attention because of its importance in discussions of the rigour of grounded theory studies. To conceptualize and formulate theory as it emerges from data, the researcher needs to be theoretically sensitive (Glaser & Strauss, 1967). Theoretical sensitivity has been described by Glaser (1978) as “the researcher’s knowledge, understanding, and skill, which fosters his generation of categories and properties and increases his ability to relate them into hypotheses and to integrate the hypotheses according to emergent theoretical codes” (p. 27). By developing theoretical sensitivity, the researcher would recognize significant data and formulate theory that is conceptually dense. While Glaser (1978) argued that theoretical sensitivity is enhanced when the researcher enters the setting with very few predetermined
ideas, I have entered the research setting with some experience interacting with families of children with FASD, and through educational experiences, familiarity with the literature. In Chapter 4, I describe how I dealt with my previous experiences.

3.4 Summary

Methodological and epistemological issues in qualitative research are difficult to resolve. In this chapter, I have presented the key tenets of symbolic interactionism. I have examined the strengths and limitations of the guiding theory. To be reflexive about filters that may come into play during data collection and interpretation (Tan & Hall, 2007), I have attempted to resolve some of the methodological issues presented by using symbolic interactionism as a theoretical lens and classical grounded theory as the strategy of inquiry. I discussed how leveraging grounded theory and symbolic interactionism can address some of the criticisms against symbolic interactionism. While following Glaser’s approach to analysis, I discussed points of departure in framing the research questions and in applying the criteria for rigour. The next chapter describes the research method used for the study, which attends to the methodological issues that have been raised.
Chapter 4: Method

4.1 Introduction

In this chapter, I describe my study design and provide definitions of the research terms. I list the research questions and discuss ethical considerations, data collection procedures, theoretical sampling, data analysis and theoretical memos, and my approaches to rigour. Because of the interplay between data collection and analysis in grounded theory, the stages in grounded theory research overlap. The overlap is reflected in the discussion of the features of grounded theory.

4.2 The Study Design

The purpose of my study was to explain how primary caregivers of elementary school-aged children with FASD in British Columbia manage their children’s schooling. My specific aims were to explain: how caregivers of elementary school-aged children act to manage their children’s schooling; contextual factors that affect caregivers’ efforts to manage their children’s schooling; and how contextual factors affect primary caregivers’ efforts to manage their children’s schooling. The nature of my purpose and aims guided me to select a qualitative research design. Specifically, I chose grounded theory as a strategy of inquiry because my intent was to generate a substantive mid-range theory grounded in data from caregivers of school-aged children with FASD. I aimed for a theory to conceptualize and explain how caregivers continuously processed their main concerns.

I used the main features of the grounded theory strategy throughout the research process: concurrent data collection and analysis; theoretical sampling; constant comparative
analysis; coding and categorizing; memo writing; and generating theory. I generated my data through interviews, participant observation, and document analysis. After beginning with purposive sampling, I used theoretical sampling to guide the data collection. I used memos to elaborate on my ideas about codes and their relationships. I maintained a personal reflexive journal throughout the research process and kept account of my biases and assumptions. I developed a core category that accounted for most of the variation in the data and explained how participants continually processed their main concerns.

4.3 Definition of Terms

Primary Caregivers

Primary caregivers are defined as being responsible for the day-to-day care of their children. They may be biological mothers, biological fathers, adoptive mothers, adoptive fathers, foster mothers, foster fathers, biological grandmothers, biological grandfathers, or other long-term adult guardians of children with FASD.

Elementary School-Aged Children

Elementary school-aged children are defined as between 6 to 12 years of age, as distinguished from preschool children (birth to 5 years of age) and adolescent children (13 to 18 years of age).

Key Workers

Key Workers are “facilitators” whose mandate includes assisting caregivers and service providers of children with FASD to understand children’s needs and develop supportive environmental accommodations. They work with caregivers of children with
confirmed or suspected FASD in a variety of ways, such as, providing emotional and practical support to families (Province of British Columbia, 2007).

4.4 Research Questions

The overarching research question that guided my study was: How do primary caregivers of elementary school-aged children with FASD manage their children’s schooling? I framed the overarching question in a sufficiently open way to use data to generate further questions during the research process. Three sub-questions guided my study:

1) How do primary caregivers of elementary school-aged children with FASD act as they manage their children’s schooling?

2) What contextual factors affect primary caregivers’ efforts to manage their elementary school-aged children’s schooling?

3) How do contextual factors affect primary caregivers’ efforts to manage their children’s schooling?

The overarching question and sub-questions reflected the symbolic interactionist perspective (Blumer, 1969; Mead, 1934; Perinbanayagam, 1985).

4.5 Ethical Considerations

The proposed study was reviewed and approved by the University of British Columbia Behavioural Research Ethics Board (BREB) for Research Involving Human Subjects. Initial approval was received December 18, 2008. Support was also obtained from a child development centre, mental health organization, and school district. As part of the recruitment process, I developed an advertisement (Appendix A), information letters for
potential participants (Appendix B), and consent forms (Appendix C). I submitted these to key workers and other contact persons at various agencies.

Although ethical considerations are introduced in this section I incorporate ethical considerations where relevant throughout the chapter. For example, addressing the power imbalance between me as the researcher and my participants is not only an important ethical consideration, but is also important to my discussions of rigour, data collection, and data analysis. I begin by addressing the issues around informed consent. Then I discuss the ways in which I attempted to address the power imbalance between me and my participants, the prevention of dual relationships, and the remuneration of research participants. A dual relationship exists when a professional engages in more than one relationship with a client (Kagle & Giebelhausen, 1994); for example, when an individual acts as both researcher and clinician.

4.5.1 Informed Consent

Sixteen potential participants contacted me by telephone and three potential participants contacted me by e-mail. Most potential participants had already received a copy of the information letter (Appendix B) through their key workers by the time they contacted me. I mailed a copy of the information letter to potential participants who responded to advertisements on the website or received information from friends in advance of the first meeting with me. When potential participants responded, I filled out an intake form to ensure that these individuals met the initial inclusion criteria (Appendix D). Seventeen potential participants who contacted me met the criteria and were selected for participation in the study. Two potential participants were not included because they lived in the United States.
Participants had, on average, 7 to 10 days to review the information letter and the informed consent letter prior to the first interview. I contacted participants one day before the first meeting to confirm their interest in participating in the study. No participants withdrew after the initial telephone contact or after they reviewed the information letter.

During the initial and follow-up telephone conversations, I gave participants opportunities to ask clarifying questions. At the first meeting, I discussed the nature of the study, including issues around confidentiality and limits to confidentiality. I showed participants copies of the interview guide (Appendix E) and observation guide (Appendix F). I also emphasized the likelihood of adding new questions as the interviews progressed. Despite the steps described above, the process of informed consent is not straightforward in qualitative research. For example, Haverkamp (2005) pointed out that the fluid nature of qualitative research prohibits identification of all factors that might influence a participant’s decision to consent. She encouraged researchers to view informed consent as a mutually negotiated process.

The following example demonstrates the ongoing nature of the informed consent process: A grandmother of a school-aged child shared painful memories and details of her adoptive adult son’s spiral into alcoholism, as well as issues around abuse – topics that she might not have planned to address when consenting to our interview. I offered to stop recording the interview at that point; however, she declined. After the interview, we discussed the nature of the information she had shared and decided to review the transcript at a second meeting to make sure that she felt comfortable about including the information in the study. On another occasion, when an interviewee ventured into an unexpected and
potentially upsetting topic, I switched off the recorder to renegotiate the participant’s consent.

Confidentiality and anonymity can never be absolutely guaranteed in qualitative research (van den Hoonard, 2003). Haverkamp (2005) pointed out that the use of extensive quotations to highlight experiences may make it difficult to protect a participant’s identity. I tried to protect the identities of participants and third parties mentioned in quotations by eliminating comments that could identify people.

Because the emphasis of a grounded theory study is on behavioural patterns, rather than personal patterns (Glaser, 1978), I informed participants that the final write-up would not include any identifying personal information. I assured participants that all of the information (audio-tapes, CDs, memory sticks, and hard copies) would be stored in a locked filing cabinet in my office while the study was being conducted, and that all electronic files were password-protected. I also informed the participants that a professional transcriber would transcribe the interviews and, prior to undertaking transcription, she would sign a confidentiality statement (Appendix G). No identifying information (e.g., first or last names) appeared on the transcripts; instead, code numbers were used. I stored the code numbers and names in separate locations under lock and key.

4.5.2 Addressing the Power Imbalance

A power imbalance exists between researchers and participants because the researcher sets the research agenda (Gubrium & Koro-Ljungberg, 2005; Kvale, 1996). I tried to address this imbalance through purposeful actions during the research process. I started interviews with a broad and general question: “How do you manage your child’s schooling?”
I also attended to the power imbalance issue by offering participants choices for where, when, and how long to meet and respecting the timelines suggested for interviews. Following transcription, I gave participants an opportunity to respond to the transcripts and categories that I developed. I offered follow-up meetings with all participants as soon as I received the transcripts to provide opportunities for participants to read through their transcripts and raise any questions or concerns. I also attended to any needs for additional support for caregivers and the necessity of recording second interviews.

Fourteen participants were interested in meeting to review their transcripts; they took time to read through their transcripts in their entirety and comment on the typed dialogue. One participant asked to keep a copy of the transcript for her own records. Two participants made changes to their transcripts; one change pertained to the protection of confidentiality, and the other change was to emphasize that the participant’s son was adopted. Because of the potential emotional distress arising from talking about FASD and the potential stigma associated with requesting support, I provided all participants with a contact list for potential supports prior to the first interview. The list included contact information for key workers, parent support groups, and support agencies in each community in the Lower Mainland. Following a request, I provided one participant with an additional opportunity to connect with a support group outside of the area where she lived.

Because understanding the meanings that participants made of their experiences depends on rapport-building, among other factors (Morrow, 2005), I decided not to record some of the second interviews, instead, I made detailed notes while interviewing. For example, during an interview in a coffee shop the recorder attracted some attention from the other patrons, so I took notes. When a partner’s career elicited a lengthy conversation about
the confidential storage of recorded information from the first interview I decided to take notes at the second meeting. When detecting any hesitation about tape-recording an interview I used note-taking. Removing a symbol of the power differential (the recorder) between me and the participant decreased power differentials and facilitated rapport. Given that concepts and patterns, not precise descriptive accounts, are important in a grounded theory study, I decided that the benefits from continued rapport-building outweighed any shortcomings from omitting the digital recordings. Glaser (1998) discouraged the use of tape-recording altogether.

### 4.5.3 The Prevention of Dual Relationships

I regarded prevention of dual relationships as another important ethical consideration. My role as an intern school psychologist in a school district introduced the potential for dual relationships: having a professional relationship with a caregiver in my capacity as a school psychologist and simultaneously developing a relationship in my capacity as a researcher. School psychologists make decisions that affect students’ educational careers and potentially their careers after school. The power differential between psychologists and families can continue until the student graduates or until the family leaves a particular school district.

School district clients, who are aware of power differentials between a psychologist and themselves and the implications for their children, might consent to the study against their will. Bourdeau (2000) argued that professional relationships characterized by a high power differential, long duration, and indefinite termination, can increase potential for harm to clients. To prevent any potential for dual relationships, I did not recruit participants from
the district in which I was working. Thus, I refused information from a key worker in that district about potential clients.

4.5.4 Remuneration of Research Participants

A final ethical issue I discuss in this section revolves around the remuneration of research participants. I believed that remunerating participants for taking time out of their lives was important. I considered what would be an appropriate amount for compensating participants for their time while providing compensation at a level to avoid being coercive (Ensign, 2003). At the first meeting, I paid participants $25.00 for their participation in the research project. Two participants declined payment. No participants received remuneration for follow-up interviews. I determined need for childcare fees at the first telephone contact. Because most interviews took place during school hours only six participants requested fees to cover the cost of childcare for younger children at home. The average cost of childcare fees was approximately $20.00.

4.6 Data Collection Procedures

In the following sub-sections, I describe the data collection procedures, including sampling techniques and data collection strategies. The data collection strategies included interviews, participant observation, and document review.

4.6.1 Sampling Techniques

I used purposeful sampling to access the caregivers of school-aged children with FASD who could talk about managing their children’s schooling. Glaser (1978) indicated that sampling variation should not be predicated on demographic variables; rather, any
indicators of variation should earn their way into the data based on theory development. Nevertheless, I was also interested in including biological caregivers in my sample because they have been under-represented in qualitative studies.

The study took place in the Lower Mainland of British Columbia, which was selected because it was important for me to interview participants face-to-face near their areas of residence or in areas that were familiar to them. For practical reasons (e.g., time and cost), I interviewed only caregivers who lived within a three-hour driving distance from me. In providing participants opportunities to choose locations for interviewing where they would feel most comfortable, I intended to democratize the research process; however, I also recognize the underlying power dynamic inherent in the very act of “making it as comfortable as possible for the participant.” After all, during the data collection stage, the researcher depends on the participant, who owns the knowledge and can decide whether or not to disclose it (Karnieli-Miller, Strier, & Pessach, 2009).

I recruited the caregivers using a number of techniques, including placing an advertisement on the website of a provincial online information resource on FASD, accessing key workers in the Lower Mainland, and snowball sampling. Snowball sampling, or asking existing participants to identify other participants for possible inclusion in the study, is a particularly advantageous sampling method in research studies that involve sensitive issues (Faugier & Sargeant, 1997).

I contacted key workers via e-mail, telephone, and appointment. I asked the key workers to post the advertisement at their offices and to distribute information letters to interested clients. Six participants responded, based on the information they received from their key workers or other professionals working with them. Eight participants responded
based on information from other participants or through word of mouth and three participants responded to the advertisement.

Because I initiated data collection by interviewing participants who had experience in the general problem area of managing their children’s schooling, and who were able and willing to provide data about this social process (Cutcliffe, 2000; Morse, 1991) my initial sampling process included purposive and snowball techniques. As the data collection proceeded and categories and their properties began to emerge, I superseded purposive sampling with theoretical sampling (Glaser, 1978).

I began theoretical sampling after the categories and properties of categories were adequately developed, to guide my decisions about where to sample next and collect data. Because of the importance of this feature of grounded theory, I describe it in more detail in Section 4.7 of this chapter.

4.6.2 Data Collection Strategies

Data collection and analysis occurred simultaneously. Data in this study were collected through interviews, participant observation, and document analysis.

4.6.2.1 Interviews

I completed 30 in-depth interviews with the caregiver participants between February 2009 and November 2009. Of these, 17 were first interviews. I selected twelve participants for second interviews and one participant for a third interview, based on theoretical sampling. My second and third interviews were guided by tentative hypotheses. I conducted them to explore recurring patterns in the data and to flesh out some of the categories important to the emerging theory. Examples included theoretically sampling caregivers who were not single
parents; participants who were living outside a setting that had been portrayed over the long-term as a community of people living in poverty and experiencing marginalization, and later, participants who lived inside this community; participants whose children attended special schools or programs; participants who did not attend support groups; participants who were not biological parents; and participants who were not connected to key workers. I describe how I determined the need for second interviews in Section 4.7.

First interviews lasted for approximately 70 minutes, while second interviews ranged from 30 to 45 minutes. I conducted second interviews approximately two months after the first interviews. In one case, I scheduled the second interview four months after the first interview. I interviewed most participants in their own homes, although some participants were interviewed in private spaces at community centres or coffee-shops.

Using both a cassette and a digital recorder, I audio-recorded initial interviews. Interviews were typed and transcribed verbatim by a professional transcriber and typically returned within two to three days. After I received the transcribed interview, I read through the transcript in its entirety while listening to the audio-recording. I corrected any inconsistencies between the recording and the transcript. Interviews were typed in the left two-thirds of the page, and each line was numbered in the far left margin. The right third of the page was left blank for my coding.

Although I developed a semi-structured interview guide (Appendix E), asking questions from the interview guide proved to be unnecessary for most of the interviews, because the caregivers often addressed question topics spontaneously during the interview. A general question was asked to open up the conversation. The question did not change much over the course of the research process; for example, I would ask, “Tell me how you manage
your child’s schooling.” I encouraged elaboration during the interviews where necessary, although I was careful to avoid imposing any of the categories I was constructing through my questioning. Follow-up questions were often related to process rather than content. I questioned for meaning; for example, “You started off by saying, ‘keeping things on track.’ I am curious to know what that means?” or, “If you say you brought that up (to the teacher), what would that look like?”

Over time, and guided by my memos, new questions emerged that I used to elaborate my categories to further theory development. For example, questions that followed the first few interviews included, “Some parents have told me they feel quite isolated in managing the schooling. Some parents have described connecting to a support group. I am curious to know what you do.” I also made statements that helped me to elicit responses that aided in comparing and contrasting incidents. For example, I asked, “It is interesting that you’re saying this because I’ve talked to some parents who said being on standby and being there 24/7 means you say no to a promotion or it means that you cannot work at all” or, “Some parents tell me you can’t go into the school and tell them what’s on your mind. You kind of have to be a bit strategic… you have to mind your ‘p’s and ‘q’s. Do you have a sense of that?”

Later in the process, I used visual representations of the developing theory during the interviews. The visual representations illustrated the relationships between categories; participants were invited to provide feedback on them, which was incorporated into the developing theory. That process helped me to further develop the theory and relationships between the core category and other categories. Appendix H shows an example of a visual representation that was presented to caregivers. On occasion, after re-reading the interviews,
I noticed places where my own responses or biases may have affected the participant’s response. I noted these occurrences in a personal reflexive journal, and then checked the participants’ responses in these sections against the data gathered at different points in the process. Constant comparison helped me to develop hypotheses, which were grounded in the data, rather than developed from my own assumptions.

### 4.6.2.2 Participant Observation

I undertook 25 hours of participant observation in participants’ homes and other interview contexts. I documented participant observation data as field notes in a notebook. I typed up field notes shortly after I returned home from an interview (Appendix I). The data provided a record of what I had observed, along with notes on my interactions with the participants. Notes were also made before the interviews, for example, while I was waiting for a participant, during the interview, and immediately following an interview. I used the participant observation guide (Appendix F) to guide my observations. My field notes included references to interactions between me and participants, interactions between family members, and participants’ physical gestures, and tone of voice. I also made detailed notes of the location of the interview, room organization, and home environment.

The field notes allowed me to follow up in interviews to determine what symbolic meanings non-verbal comments (e.g., gestures) had for participants. Reviewing the notes together with the audio-recordings helped me to start the process of writing memos and plan for the next interview. I analyzed the field notes similarly to the data from the interviews. The notes also helped me frame questions for future interviews. For example, I visited a family in a remote area of the study recruitment area where I encountered several
geographical barriers before reaching their home. I noted the features of the location in my field notes and commented about how they might contribute to a sense of isolation for the family.

At that point, I was interested in exploring the category, “isolation,” that I developed from previous interviews; I could use my observations to stimulate conversation about the topic. For example, in addition to my observations, the following excerpt was taken from the interview:

I didn’t… and then when we had… we have a very steep hill. Bad winter days we’d have… you know… snow days… and we’d work at home in school… in spelling and math and reading and whatnot. And I was realizing that they are so far behind they don’t understand the simplest things… and I’m still a little… you know… I’ve been a little afraid to speak up… like who am I when they’re the professionals? (11.1, lines 65-75).

Participant observation also helped me to find points of correspondence between what people said and what they did. Noting an advertisement on the wall for food bank locations and hours of operation when I interviewed a participant sensitized/alerted me to the information contained in the following interview excerpt:

And I talked to her [the principal], and man, I never had no problem with her. So that’s why I’m looking forward to this year. That’s why the first day of school there I got to debate if I’m going to go to the Food Bank [or go to see the principal] (14.1, lines 612-615).
Observation and interview data helped me to write memos about the influence of poverty on actively managing schooling. Later, I went back to my notes and interview data when I developed the category, “keeping up appearances,” and the conditions that influence the ease or difficulty for caregivers in keeping up appearances. The early memo served as a small building block that contributed towards my development of the core category and the theory.

In another case, when the participant commented on how time-consuming it was to manage life with a child with FASD, I observed on her refrigerator a multitude of notes for medical appointments and assessment dates. On another occasion, I noticed a caregiver at a conference who had set up a booth with information about an FAS helpline that she had started, several months after she said the following in an interview:

And that’s, you’re asking about [visiting the MLA] …again, that’s something that I went there to propose or to ask her about how I can do this. I want a 1-800 info FAS line, because I am sick and tired of hitting brick walls (5.1., lines 494-497).

In the preceding case, I followed up on an observation that I made before the interview began when I asked the participant about a note lying on her kitchen table that had the name of her MLA on it. My observations before and after the interview contributed to the memo, “advocating and educating.”

Participant observation also allowed me to access meanings that were communicated through non-verbal behaviour, as illustrated by the following excerpt from a second interview:
And my doctor… I go to see my doctor because at this point… all the guilt… all the guilt comes back. Like I did this to her (emphasize, very emotional, crying, resting head on arms). And I can’t even help her (5.2, lines 143-145).

In this case, the data from the participant observation was labeled, “overcome with guilt,” and it contributed to an early category, “hitting the wall.” I used the early code, “hitting the wall” to label incidents where actively managing was relinquished momentarily or for a longer time.

Participant observation also enabled me to note points of resistance between what a caregiver was prepared to say and their actions. One caregiver expressed confusion about how the disorder came to be, even though she had mentioned being a “social drinker.” She generally preferred to focus on her child’s additional diagnoses during most of the interview, although I observed that she had many books and other sources of information about FASD in her home. Early in the interview, I commented about the FASD resources; as our rapport continued to build during the interview, the participant became more comfortable about raising the topic. The initial tension, between what was observed and what the participant chose to talk about during the interview, contributed to an early memo, “saving face,” which was eventually renamed, “keeping up appearances.”

Following my second meeting with the caregiver who wanted me to emphasize that her son was adopted, I reflected on her request in my observation notes after the meeting. The caregiver felt that it was important to emphasize that her son’s brain damage due to prenatal alcohol exposure was not caused by her. I later compared my notes with other data that eventually also contributed to the category, “keeping up appearances.”
Many of the parents had special treats available during my visits and I made notes about their presentation of food. Having been sensitized by my observations in the homes of the participants, I questioned a later participant about the meaning she attached to food and her efforts in presenting food; she commented that it made her feel like a good parent. Later, I returned to these notes and integrated them as part of my development of the category, “keeping up appearances.”

After a visit to one of the adoptive parents, I made a note about her refusal to accept the money for the interview. A second participant also refused payment for the interview. The adoptive parent commented that it did not feel like the “right thing,” to discuss her child and accept money in return. Later, these field notes contributed to my development of the category, “keeping up appearances,” in which I compared and contrasted incidents from the data about avoiding being viewed as a “bad” parent.

On another occasion, while interviewing a biological mother, she referred to a time in her child’s life when the child stayed with a “foster parent,” and then she immediately corrected herself by saying, “I mean, good parent.” This correction also contributed to my memo, “saving face.” At a second interview, in the context of growing trust, she revealed that her child’s stay with a foster family made her feel like a bad parent, which compounded the guilt she felt about her child’s exposure to alcohol. These revelations may not have been revealed to others. Along these lines, Glaser (1965) remarked that, because research studies into social problems “raise problems of secrecy, sensitivity, taboo topics, stigma… and because people in these situations are usually adept at covering the facts when necessary” (p. 436), a combination of data collection methods (including interviews, observation, and document analysis) is needed.
4.6.2.3 **Document Analysis**

I received documents from participants, such as e-mails, newsletter articles, letters to the principal and various teachers, letters to the newspaper, assessment reports, and video material, and incorporated them as data. I coded the data from document analysis in the same fashion as the interviews and observations (Glaser & Strauss, 1967). After analyzing numerous letters sent to the principal, along with the interview data, I developed the categories, “pitbulling” and “cultivating connections.” By analyzing the hand-written letters and e-mail correspondence between school principals and caregivers, I could better identify the conditions when pitbulling and cultivating connections would be more difficult. Glaser and Strauss (1967) pointed out that different “slices of data,” (p. 65) provide the researcher with different vantage points from which to develop the properties of categories. Information from policy documents (e.g., educational policies) and information from documents passed on by professionals who were working with families with FASD were integrated after I had identified the core category (Chapter 6).

4.7 **Theoretical Sampling**

Glaser and Strauss (1967) describe theoretical sampling as follows:

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges (p. 45).
Theoretical sampling and the constant comparison method are used jointly and continuously from the outset of data collection until each code is saturated, elaborated, and integrated into the emerging theory (Glaser & Strauss, 1967).

The purpose of the constant comparative method is to generate theory systematically by using explicit procedures for coding and analysis. Glaser and Strauss (1967) stated the defining rule for constant comparison: “While coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category” (p. 106).

I entered the first set of interviews with questions based on my perspective of the general problem area of how caregivers of children with FASD manage their children’s schooling. I began the process of theoretical sampling after I developed some initial categories and their properties. Guided by the data, and the initial categories and their properties, I made comparisons between kinds of information to generate qualifying conditions. The process of conceptual elaboration helped me to form tentative hypotheses, which further guided my data collection. For example, while I did not assume students’ schools were important conditions at the outset, early responses from caregivers indicated that their actions to manage varied depending on the kind of program their children attended. Notwithstanding the willingness of a key worker to suggest caregivers who lived in the district where the first participants were interviewed, I decided to select interested participants from diverse districts next. In this case, theoretical sampling helped me to develop the category, “being on stand-by,” and to explore conditions (e.g., knowledge of FASD) that influenced the caregivers’ actions and the consequences that flowed from their actions.
Later, I sought to interview caregivers with children who were attending programs specifically for children with FAS. After applying for ethical clearance from the University of British Columbia and research approval from the specific school district, I sent information to key people in the school district that was hosting the special program. Because the participants were not forthcoming through contacts in the school district and sampling of the caregivers was important to the theory development, I tried to access participants from the programs via key workers and participants. I also conducted second interviews with participants and a third interview with one participant to develop my tentative hypotheses. I interviewed one participant three times because her child’s school placement had changed over the course of the research project. Thus, her child had moved from attending a regular program to a program for children with social development issues and finally a program for children with FAS. Theoretical sampling, in this case, helped me to develop the category, “islands of success,” which was later renamed, “islands of calm.”

Another example of how the tentative hypotheses guided my theoretical sampling revolved around the indicator of single parent status. Most of the participants I initially interviewed were single parents. The data I obtained from the interviews suggested that the caregivers needed to be at the school “24/7” to actively manage their children’s schooling, which affected the caregivers’ abilities to engage in paid employment. I wrote the following process memo following the fifth interview on April 9, 2009:

The group of caregivers I have talked to, to date, were all single parents and none of them were working full-time. One might expect a category such as “being on stand-by” to be influenced by employment status. How are you on constant stand-by if you
need to work? How would that influence their behaviour? Also, is managing the schooling easier for caregivers when there are two parents? I could add usefully to the sample by identifying and talking to caregivers who are working and caregivers in relationships/married.

I wanted to explore whether or not single parent status was an important indicator. I was interested in how being single versus being in a relationship influenced the dynamic interplay between what I coded at that point, “what caregivers want for themselves” and “what caregivers want for their children.” At that point, I specifically sampled for caregivers in relationships, again, holding back from sampling participants who were not in a relationship. As the analysis progressed, it became evident that single mothers were just as likely to “advocate” or “keep up appearances” as single fathers, or caregivers in relationships. Nonetheless, the single status made the full-time management of the children’s schooling, and being on stand-by, more difficult, especially for caregivers who were single and poor.

As the data collection and analysis proceeded, an indicator that I recognized as conceptually important pertained to living in a setting that had been portrayed over the long-term as a community of people living in poverty and experiencing marginalization. I sampled more caregivers in that setting and also returned to interview some participants for a second time to explore how living in a close-knit community, which was the way the community was framed by the caregivers, influenced caregivers’ actions to resolve their main concerns.

Another example of theoretical sampling revolved around the category, “staying connected.” I was interested in how being connected to a support group helped the caregivers manage “what they want for themselves” (or their “success as a parent”) and “what they want
for their child” (or the “success for child”). Because the first three caregivers I interviewed attended some form of support group I sampled specifically for caregivers who did not belong to a support group. Theoretical sampling, in this case, provided me with diverse conditions to further develop the category, “keeping up appearances.” To summarize, it is the comparison of differences and similarities in the data that facilitates the generation of categories, their properties, and their interrelations (Glaser & Strauss, 1967).

While concurrent data collection and analysis are important features of grounded theory research, Jeon (2004) pointed out that contingencies of time and resources may require some adaptability on the part of the researcher. At times, referrals for the study came in quickly (at one point, two referrals per week). Given the sensitive nature of the topic being studied, I did not want to delay interviews until my analytic efforts pointed me to the groups or subgroups to which I would turn next to further my development of the theory. Interviewing some participants before memos were sufficiently developed to indicate where to sample next (theoretical sampling), might have led to some redundancy in interviewing and kept me from asking questions that could have facilitated my ability to develop more properties for some categories.

4.8 Data Analysis and Theoretical Memos

Because my data analysis took place concurrently with the data collection I wrote memos continually throughout the research process. The memos are “the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding” (Glaser, 1978, p. 83). I wrote both theoretical and process memos. My theoretical memos took the shape of text and visual models. Initially, the memos came from the constant comparisons of
indicator to indicator and indicators to concepts. Later, I generated memos by sorting and writing-up, as suggested by Glaser (1978). I also wrote process memos to make my research process clear. Process notes dealt with methodological issues; for example, I wrote notes indicating my next step in the data collection.

I continued to write memos while reworking the first and second drafts of the chapter describing my theory. During reworking of my drafts, by revisiting earlier memos, constantly comparing within and across interviews, and using the process of “one-upping” with members of my research committee, I developed the core category, “intertwining to fit in.” The process of “one-upping” is described, by Glaser (1978), as “a collaborative theoretical effort to refine the level of the data as quickly as possible while carefully fracturing it” (p. 59).

I analyzed the data line-by-line and wrote codes in the margins of the transcribed interviews, field notes, and documents. I considered using computer-aided qualitative data analysis software for its advantages (rapid data processing) and to manipulate the data without changing the original set (Jones, 2007) but I decided to code the data by hand. I believed hand coding increased my familiarity with the data and my facility with incorporating codes into memos.

In deciding not to use software, I was swayed by Glaser’s (2005) argument that “going conceptual” (p. 39) would be stultified by computer technology. On a separate sheet, I tabulated the codes with their corresponding line numbers to keep track of the location of the codes in the transcript. I constantly interrupted the coding process to type memos. At times, when conceptual ideas emerged when I did not have access to a computer I wrote memos on paper and entered them in the computer later. I kept adding to the memos until I developed
the core category, which integrated the memos. Then, I sorted and wrote theoretical memos in the final steps of the grounded theory method.

In the next subsection, I describe the constant comparative method of analysis, with reference to the different levels of coding that I used. To demonstrate the process of developing codes, I refer to memoing in the sections below.

### 4.8.1 Constant Comparison Method of Analysis

I used the method of constant comparison jointly with theoretical sampling. My recursive data collection and analysis process ensured that I constructed a theory that was grounded in data gathered from caregivers. The purpose of the constant comparative method in grounded theory research is to assist with conceptualization and categorization in the course of data collection and analysis (Glaser, 1978; Jeon, 2004). By using the coding and analytic procedures made explicit by Glaser, I generated categories, properties of categories, and hypotheses about relationships among categories.

The unit of analysis in grounded theory is the incident (Glaser & Strauss, 1967). Constant comparison of incidents within and between interviews, field notes, and documents continues until no new properties or dimensions emerge through the continued coding and comparison. After fracturing and coding the data on the basis of incidents, I clustered codes into categories. I then compared more incidents to my categories. In the final stages, I integrated the categories and their properties, delimited the theory, and wrote the theory (Glaser & Strauss, 1967). Throughout these stages, I developed different levels of categories, as described below.
4.8.2 Coding

Codes are the “essential relationship” (Glaser, 1978, p. 55) between data and theory and conceptualize the underlying pattern of a set of empirical indicators in the data. After I generated some initial codes and clustered them into categories, two types of coding (substantive and theoretical) occurred simultaneously (Glaser, 1978, 1992, 1998; Glaser & Strauss, 1967). While substantive codes conceptualize the empirical substance of the problem area, theoretical codes conceptualize how, integrated by the core variable, the categories relate to each other (Glaser, 1978, 1998). Substantive coding carried more of the emphasis as I constructed codes in the data, while theoretical coding carried more of the emphasis as I was sorting and integrating my memos to develop more abstract categories and their relationships (Glaser, 1978). Substantive coding, as described by Glaser (1978) consists of open coding and selective coding.

4.8.2.1 Open Coding

During open coding, I coded transcripts on a line-by-line basis. I coded the data “for as many categories that fit” and in “every way possible” (Glaser, 1978, p. 56). The analysis of the first interview took place over five days, and yielded over 150 open codes. During coding, I took care not to assume the analytical relevance of any variable, such as sex, age, relationship status, or income. Glaser emphasized that variables “are never necessarily a property of the process under study until discovered so” (Glaser, 1978, p. 60).

While interrogating the data, I continually asked the following questions: “What is this data a study of?” “What is going on here?” “How is the caregiver managing the situation?” and “What categories are suggested by what is going on?” These questions helped
me to work at a conceptual level, rather than providing detailed descriptions of incidents (Glaser & Holton, 2004). Furthermore, I constantly interrupted the coding process to write memos (Appendix J). The second interview was coded with the first interview in mind, while I added to my memos.

To develop categories from subsequent interviews, field notes, and documents, I continued to ask questions: “What category does this indicate and what property of a category does this incident indicate?” Glaser and Strauss (1967) described a category as similar incidents that are grouped together and given the same conceptual label and property as an element of a category. At times, I used the caregivers’ exact words, or “in-vivo codes,” to vividly illustrate the meaning of incidents. Examples include “walking on egg shells” and “minding your ‘p’s and ‘q’s.” I clustered together similar incidents, such as “walking on egg shells,” and “minding your ‘p’s and ‘q’s,” and initially assigned the conceptual label, “working around the system.” Later, I renamed the category “treading carefully.” I clustered together incidents, such as “keeping at it even when it kills you,” “pushing back,” “pushing until you get help,” “not accepting no for an answer,” “non-stop action to find support” and “not backing down”, and assigned the label “standing firm.” I clustered together incidents such as “persistent asking,” “persistently calling,” and “getting people in” and assigned the label “hauling in support.” I then clustered together the categories “standing firm” and “hauling in support” as properties or sub-tactics of the category “pitbulling.” I eventually collapsed the category “treading carefully” into “pitbulling,” where “treading carefully” became a way to moderate pitbulling. As I continued to write memos, I “trimmed and fit” (Glaser, 1978, p. 60) some of the early categories. I renamed categories as I tried to best capture their meaning. For example, the category “actively managing schooling” was
renamed, “orchestrating schooling.” An initial code, “moving” was renamed “changing settings for fitting in,” as I continued to work at a conceptual level. The category “hitting brick walls” was renamed “hitting rock bottom” to better fit incidents of being cut off from others; intense exhaustion; and guilt, layered with grief.

Analyzing the data line-by-line was a painstaking process. As mentioned before, I analyzed the first interview over five days, spending approximately 25 hours in the process. After interviewing the first five participants, I found that the coding process became more fluid. New incidents also began to fit into existing categories. Simultaneously, I constantly interrupted the coding process to write memos.

After the fifth interview, I had written 25 memos with titles, such as management strategies, support, saving face, advocating and educating, hitting brick walls, guilt, connecting, isolation, trying to keep myself on-track/trying to keep my child on-track, the nature of FASD, conditions in the school-environment, (child) fitting-in, living in a close-knit neighbourhood, self-care, understanding of FASD, preserving self/preserving child, and the nature of the relationship between parent/child. The memos varied in length from a sentence to a few pages. I developed visual images from early interviews and captured them in memos including, for example, an ongoing roller coaster ride, where getting to the top of the hill only lasted for a short while before the cycle started again. I also tried to visually represent the “connection” between caregivers and their children by drawing two figures who were trying to balance opposite sides of a windsurfer. In a second visual, I drew a parent and child pulling on opposite ends of a stretched-out cord, trying to adjust the tension so that it would not break.
After analyzing approximately 26 of the 30 interviews, and the field notes, I was developing no new categories. I found that almost all of the data could fit into the existing conceptual categories. I was generating no new incidents and the same properties emerged over and over again. For example, the category “hitting rock bottom” became saturated relatively quickly, with caregivers repeatedly referring to exhaustion, disengaging, giving up, and for biological caregivers, guilt. The conditions that influenced “rock bottom” were also clear. I developed the category “keeping up appearances” with its properties more slowly. Because I felt that some properties of the category “keeping up appearances” were not as well developed I ran the data open almost to the very end of the research process and referred back to earlier memos to try to saturate the category.

4.8.2.2 Selective Coding

According to Glaser (1978), selective coding follows open coding and the emergence of a pattern marked the start of selective coding. In the study, the core category that I developed was “intertwining to fit in;” it did not “emerge” as suggested by Glaser (1978). Instead, I developed and refined it over time by using strategies such as constantly comparing the data, re-reading and writing memos, drawing visual presentations, and engaging in “one-upping” conversations with my supervisors. I continued to think conceptually about how caregivers tried to process their main concerns, which were identified early on, although I refined how I labeled the main concerns over time. During selective coding, I explored how the developed categories were related to the core variable, and which kind of core variable would best capture most of the variability in the data. In developing the core category, I
referred to the memos and re-read the transcripts, with reference to Glaser’s (1978, 2005) work on core categories.

My process of constructing the core category included several “re-starts.” I had written many pages exploring “balancing” as a core category, through which the caregivers tried to process their concerns for themselves and their children. I saw caregivers’ attempts to obtain success for their children in school as detracting from their own self-preservation, which was contributing to their hitting rock bottom. By re-reading the transcripts and memos and in the process of one-upping with the grounded theory researcher on my committee, I determined that the caregivers and their children were not in balance or imbalance, but were “intertwined:” success for children and parents were threatened or made easier, simultaneously. I returned to an early memo, entitled, “the nature of the relationship,” and the visual representations that captured the “essence of relevance” (Glaser, 1978, p. 94) that reflected the data. Although I had captured the essence of the core variable in early memos, I did not use the “intertwining to fit in” label until much later.

After writing 75 pages exploring a core category, which I named “intertwining,” I considered whether or not it represented a basic social psychological process (BSPP). While I captured change over time, Glaser (1978) also suggested that a BSPP has at least two distinct stages. Caregivers actively managed and hit rock bottom; however, it was not clear that they moved into a distinct second stage. Glaser’s (2005) description of the theoretical code, “cycling,” seemed to fit the pattern that was captured by the core variable. According to Glaser, cycling refers to repeatedly going over the same path or different paths in succession, and to actions or interactions that spiral downward and upward. I determined that the core category, “intertwining to fit in,” represented a cycle that accounted for most of the variation
in behaviour for processing caregivers’ main concerns of preventing their children from failing academically and in social interactions, and, preventing themselves from being regarded as “bad” parents.

The following example demonstrates my selective coding. I clustered the categories, “standing firm” and “hauling in support,” (described earlier) as properties of the category “pitbulling.” The category, “treading carefully,” which I originally conceptualized as a property of actively managing, was subsumed as a property of “pitbulling.” In the stage of theoretical coding, I conceptually sorted the category, “pitbulling,” and related it to the core category, as one of four tactics for the strategy, orchestrating schooling.

Glaser (1978) suggested that the generation of theory occurs around a core category. In delimiting the theory to one core category, I moved other variables into a role that was subservient to the category in focus and integrated them in terms of that (core) category. The core category integrated the codes by capturing the pattern of behaviour that was relevant and problematic to caregivers with as few concepts as possible. I only included variables that were significantly related to the core category. For example, the category “maintaining structure” was not integrated into the theory because it was concerned with how caregivers managed their home lives with children with FASD. I did not regard the category as relevant to the research question and the core category. My process for finding the variable that accounted for most of the variation in the data, the core category, is detailed in my memos (Appendix K).

The core category had integration, saturation, density, completeness, and a delimiting focus (Glaser, 1978, 1992). According to Glaser and Strauss (1967), the “criteria for determining saturation… are a combination of the empirical limits of the data, the integration
and density of the theory and the analyst’s theoretical sensitivity” (p. 62). To decide whether or not I had reached saturation, I asked myself if I could saturate the categories and relationships that were integrated by the core category, “intertwining to fit in.”

4.8.2.3 **Theoretical Coding**

After selectively coding for a core category, I began the theoretical coding to indicate how, integrated by the core category, categories were related to one another. Theoretical codes are used to explain integrative patterns. While I was aware of Glaser’s (1978, 2005) coding families, I carefully developed the theoretical codes through relating substantive codes, and the categories to each other, rather than attempting to force Glaser’s coding families onto the process. Glaser’s coding families therefore served as sensitizing concepts, “merely (suggesting) directions in which to look” (Blumer, 1954, p. 7). As outlined by Glaser, I used some of the theoretical codes that fit the data, to weave substantive codes together into hypotheses and a theory. The codes included: outcomes, conditions, strategies, tactics, critical junctures, degree, and cycling. For example, categories such as “pitbulling,” “being on stand-by,” “cultivating connections,” and “anticipating difficulties” were related to the core category as tactics for orchestrating schooling. The categories “adjusting the flow of information,” “reframing,” and “redefining self.” were related to the core category as tactics for “keeping up appearances.” The categories “orchestrating schooling” and “keeping up appearances” were related to the core category as strategies by which caregivers intertwined to fit in.

Although the category, “spiraling out of rock bottom” developed early on, it was not until I began the theoretical coding that I renamed the category “re-engaging” and related it
to the core category as a strategy for “moving out of rock bottom.” At this point in the process, sorting and integration of memos helped me to relate properties and categories to one another and to the core category.

Throughout the process, I drew models of the developing theory, which changed over time as I developed the theory. The pictorial models facilitated my write-up of memos because they provided visual reminders of the connections between categories, properties of categories, and connections of categories to the core category. The use of visual models helped me to clarify the relationships among the categories and I continued to compare the relationships between categories with theoretical codes. This process helped me to integrate the categories into coherent theory (Glaser, 1978). As an example of this process, I have included a visual representation of the developing theory (Appendix L) and an example of my process memos at a later stage of integration (Appendix N).

I wrote 74 single-spaced pages of my chapter on the findings, which subsumed many memos. The titles of the memos included: actively managing schooling, keeping up appearances, hitting rock bottom, the educational context, living in a close-knit neighbourhood, isolation, educational policies, staying connected, preserving self, preserving child, waiting it out, shifting expectations, self as expert, changing perspectives, what parents want for themselves/what parents want for their child, running pit bull, armoring, setting the stage, strategizing, overcoming doubt, standing firm, the nature of FASD, contemplating forever, 24/7, being on stand-by, poverty, the go-to person, redefining self, and nature of the relationship between caregiver and child.

The process of “one-upping” helped me to refine the codes. For example, during one of my conversations with Dr. Hall, the code “changing perspectives” was fractured and
substituted with two codes; namely, “reframing relationships” and “reframing processes.”

The in vivo code, “running pit bull,” for example, was changed to a gerund, “pitbulling,” to better fit the intensity of the incidents that comprised the category. The strategies of constantly comparing the data, re-reading and writing memos, drawing visual presentations, and engaging in “one-upping” conversations, helped me to further refine the relationships between categories, and to integrate the theory. They also helped me to stay grounded in the data and prevented any logical elaboration that can easily occur during theoretical coding (Glaser, 1978).

4.9 Rigour

In Chapter 4, I argued rigour involved making the steps in the research process clear, taking up criteria for rigour that are relevant for the particular study, and adding criteria for rigour that account for the guiding theories. In this section, I briefly discuss auditability and theoretical sensitivity. Subsequently, I will discuss the criteria for rigour, as explicated by Glaser (1978, 1992): fit, work, relevance, modifiability, parsimony, and scope. Through Glaser’s criteria, I attended to the rigour of the research product. I conclude this section with additional criteria for rigour, reflexivity, and relationality, which also attend to the integrity of the research process.

4.9.1 Auditability

Auditability is defined as making steps in the research process clear so that another researcher can follow the audit trail or decisions made (Lincoln & Guba, 1985; Sandelowski, 1986). I employed a number of strategies to make the research process clear. I developed
process memos about the rigourous examination of the data for negative cases, and outcomes and decisions following the process of “one-upping” with an expert grounded theory researcher. The trail also included memos about my engagement in observations and how this guided my decision-making, along with notes about the fit between data and the emerging analysis. Part of striving for auditability was writing memos on when I thought I had reached saturation. I saturated most categories through the process of theoretical sampling and stopped sampling when I felt confident that my theory explained most of the variability in the data and I had saturated the categories and relationships that were integrated by my core category, “intertwining to fit in.” I also purposefully looked for negative cases and considered them when making these decisions. The following excerpt is from a memo on saturation for the “rock bottom” category, from an interview with Participant 14:

The data on rock bottom is repeating itself. I am getting the same concepts over and over. When I did coding, all of the incidents around rock bottom seemed to fit existing codes: guilt, exhaustion, disengaging, waiting it out… Conditions that influence seems to be identified: support, close knit community… I am not getting any new information.

4.9.2 Theoretical Sensitivity

Glaser and Strauss (1967) emphasized the important role that theoretical sensitivity plays in conceptualizing and formulating a substantive grounded theory. They defined theoretical sensitivity as the ability to have theoretical insight into the area of research, as well as the researcher’s “personal and temperamental bent” (p. 46). Hall (1998) emphasized that rigour in grounded theory is strongly connected to theoretical sensitivity: “When analysts
are theoretically sensitive, they are more likely to develop a grounded theory that fits, works, is relevant and modifiable, and has scope and parsimony” (p. 74).

My educational and work experiences have increased my sensitivity to caregiver-school interactions and the experiences of families of children with FASD. Hall (1998) referred to these experiences as “sources of theoretical sensitivity” (p. 74). Glaser (1978) argued that staying open to the data enhances the researcher’s theoretical sensitivity. By acknowledging the theories, exposure to the FASD literature, and educational and work experiences that I brought to the study, I strived to stay open to the data and caregiver perspectives.

4.9.3 Grounded Theory Criteria for Rigour

The criteria for rigour, as defined by Glaser (1992), include fit, work, relevance, modifiability, parsimony, and scope. Glaser defined fit as the relationship of the core category to the salient social problem and its ability to account for most of the variation in behaviour used to address the problem. A grounded theory that works will explain the major variations in behaviour in the area that attempts to address the problem to be processed in a meaningful way. If a grounded theory fits and works, it has achieved relevance. Furthermore, a core category that fits, is relevant, and works can be modified when new data present variations in properties and categories. Accounting for as much variation in the data with as few concepts as possible maximizes parsimony and scope (Glaser, 1978, 1992).

The core category fit because it accounted for most of the variation in behaviour as caregivers processed their main concerns. I also aimed for fit through a process of naming and renaming patterns in the data to capture their imagery and meaning in the best ways
(Glaser, 2002). By naming patterns through a process of ongoing fitting of the data, I was able to reach a point where the core category, categories, and properties developed appeared to fit the data very well. For example, the category “treading carefully” was initially named, “being strategic.” I changed the label to “treading carefully” because it presented a better fit for the meaning of the incidents that made up the category. Renaming categories and properties, or constantly fitting them to the data, helped me to choose the words that best captured the patterns in the data. By conceptualizing the data and moving beyond description, I expanded the individual constructions.

Because the core category explained the major variations in caregiver behaviour it worked. While the final version of the core category was not directly validated with participants, participants indicated codes and the relationships between categories and properties, as well as categories and the developing theory were relevant to their experiences. A core category that fits, works, and is relevant is more likely to be modifiable so that new data can contribute to the theory under different conditions.

The theory appeared to be parsimonious in that a few well developed categories accounted for a considerable amount of scope, rendering the theory dense and saturated (Glaser, 1978). Parsimony, according to Cutcliffe and Harder (2009), is related to the elegance and straightforwardness of the findings. Because the grounded theory I developed went beyond description to the level of substantive theory and was abstract and contained it met the criteria for parsimony. I rewrote the chapter on the findings several times, which is typical for grounded theory research, contributing to a more parsimonious theory.
4.9.4 Additional Criteria for Rigour: Reflexivity and Relationality

Reflexivity addresses the influence of investigator-participant interactions on the construction of data, while relationality addresses power and trust relationships between participants and researchers (Hall & Callery, 2001). As discussed previously, extending the criteria for rigour to incorporate reflexivity and relationality enhanced the quality of the study because it made the process of constructing the data and the theory through analysis more transparent. It also accounted for the use of symbolic interactionism as the guiding theoretical perspective. These criteria are consistent with the theory of symbolic interactionism because the social processes that influence the generation of data and, consequently, the social construction of knowledge and co-construction of meaning are acknowledged.

The notions of reflexivity and relationality are also consistent with the epistemological foundations of grounded theory (Hall & Callery, 2001). Because criteria for rigour in grounded theory, as delineated by Glaser (1978, 1992), emerged from postpositivist assumptions about the nature of knowledge the question can be asked how criteria for rigour that acknowledge the social construction of data can be integrated without creating tensions. Although contested by Glaser (2005), grounded theory is understood by most authors (e.g., Annells, 1996; Kools, McCarthy, Durham, & Robrecht, 1996; Suddaby, 2006) to be partially predicated on symbolic interactionism. Hall and Callery (2001) further answered this question by pointing out that “because the postpositivist paradigm acknowledges that reality is imperfectly apprehensible and that the research process requires critical examination, it does not preclude recognizing the social construction of knowledge” (p. 262). Further,
reflexivity and relationality deal with the process of doing grounded theory, rather than the product, which is addressed by Glaser’s criteria.

I attempted to be reflexive about “filters that may come into play during data collection and interpretation” (Tan & Hall, 2007, p. 604) by detailing my prior reading in the substantive areas, my educational and work experiences, my guiding theoretical perspective, and my research actions and decisions. I also attended to reflexivity by incorporating details from memos into my final account, and by keeping a personal reflexive journal to make explicit my decisions and ideas. While recognizing that subtle biases may be unacknowledged, I tried to keep track of any biases in my reflexive journal throughout the research process. Previous experiences enhanced my theoretical sensitivity but using constant comparison also forced me to confront potential biases that were not grounded in the data.

McGhee, Marland, and Atkinson (2007) argued that self-awareness expressed through honest memo writing underlies the process of reflexivity. As mentioned earlier in this chapter, my honest reflection helped me question how my own middle-class values affected the research process. For example, in a process memo, I noted my surprise when, during an interview with a caregiver of a school-aged child with FASD, I heard that she also raised five other children with FASD. I reflected on my surprise and commented in my journal that my reaction may have disclosed my prejudice.

Despite my best efforts to focus on process and ask clarifying questions, I noted that I sometimes responded approvingly during interviews with comments such as “good,” or even, “fantastic.” In my reflexive journal, I noted how these may have shaped the interviews. By going over my notes in the reflexive journal (which included notes made during coding, jotted down during interviews, or made while listening to the audio-tapes or as field notes
after interviews), I appreciated my effects on the data. I then checked my perspectives documented against other strands of data collected at different times.

I also used a number of strategies to address relationality throughout the research process. These were addressed in detail in the ethical considerations section (Section 4.5). They included providing participants with a chance to share their main concerns; offering participants the choice of where, when, and how long to meet; giving participants an opportunity to respond to the transcripts and categories that I produced; approaching the need for additional support in a way that minimized stigma; making decisions around recording second interviews; and providing participants with an executive summary of the research. I strived to be fair to participants at all stages of the research process. For example, I spent a significant amount of time on the informed consent process and continued to negotiate consent when needed throughout the research process. I tried to capture all perspectives.

I also addressed relationality through my style of interacting with participants. I sought to facilitate a context where caregivers felt free to disclose sensitive information, through an empathic, respectful, and congruent style. Interviews took place in a context of developing trust and caregivers often disclosed more sensitive information towards the end of the interviews. I was open about my status as a parent with school-aged children, whenever I was asked.

I used tactics, such as empathy and self-disclosure, when appropriate to democratize the research situation as much as possible, and to build rapport. Nevertheless, some researchers (e.g., Kvale, 1996) have argued that the very tactics meant to democratize the research process can actually contribute to exposing to scrutiny a vulnerable and possibly marginalized group. Kvale’s (1996) stance is supported by the work of symbolic
interactionists such as Perinbanayagam (1985) who, according to Hall and Callery (2001), emphasized that “freedom to act is circumscribed by power relationships, and ideology can be used by more privileged groups to defend their assets and constrain the patterns of activity and plans of less powerful others.” (p. 269). By creating an interview environment characterized by empathy, respect, and developing trust I may have increased participation and contributed to an increase in my power over participants. While acknowledging the intertwining actions to democratize the research process and issues of power, I suggest that my attempt to address relationality was part of my effort to achieve rigour.

4.10 Summary

In this chapter, I began with a description of the study design. Next, I provided definitions of terms, and listed the research questions, which was followed by a discussion of ethical considerations, data collection procedures, theoretical sampling, data analysis, and theoretical memos. I concluded the chapter with a description of rigour. In Chapter 5, I present the findings of the study.
Chapter 5: Intertwining to Fit In

5.1 Introduction

This chapter provides an overview of my core category, namely, “intertwining to fit in.” My core category captures the pattern of behaviour that explains how caregivers of elementary school-aged children with FASD continuously try to resolve their main concerns, which are preventing their children from failing academically and in social interactions and preventing themselves from being regarded as “bad” parents.

In this chapter, I describe the core category and categories that are related to the core category. Rather than writing the theory as past tense findings I use the present tense where possible to indicate that the theory explains an on-going cycle. I use the terms caregivers, parents, or participants interchangeably to refer to the caregiver participants in my study.

I start with a description of the study sample to provide a context for the findings and to orient the reader to the nature of the sample. I then provide a detailed description of the core category, intertwining to fit in. Because the core category integrates all of the other categories, the description of my core category serves as an overview for my theory. I follow my detailed description of the core category by briefly describing the main concerns and the long-term outcomes, including the ideal long-term outcomes caregivers are attempting to achieve through intertwining to fit in. I follow this by describing the strategy, orchestrating schooling with its related tactics and sub-tactics. I integrate conditions that influence orchestrating schooling in my description and describe how outcomes from using strategies to orchestrate schooling affect the process of keeping up appearances. Conditions that
influence keeping up appearances are incorporated in my explanation of the strategy, with its related tactics and sub-tactics. Throughout my explanations, I refer to how outcomes from using strategies to keep up appearances affect the process of orchestrating schooling and vice versa. I portray two critical junctures: hitting rock bottom and reaching islands of calm, which are influenced by conditions and associated with short-term outcomes. I conclude with a description of the tactics through which caregivers re-engage with the school system to re-enter the cycle of intertwining to fit in, followed a brief summary.

5.2 Sample Characteristics

I include a description of my sample to provide a context for the findings and orient the reader to the sample. I collected demographic information on caregivers at the first interview, using a structured guide (Appendix M). The means and ranges for appropriate variables for the entire sample are summarized in text form. I provide additional description of caregiver and child characteristics in table form (Appendix O).

Seventeen caregivers of school-aged children with FASD were included in the study. They lived across the Lower Mainland of British Columbia. The sample included six biological mothers, one biological father, one step-mother (who was a biological mother of another child), two grandmothers, five adoptive mothers, and two foster mothers. One of the foster mothers was in the process of adopting her child.

The average age of parents was 42.9 years (range 28 to 54 years), while the average age of grandparents included in the study was 59.5 years (range 58 to 61 years). Eleven of the participants were single; six participants were married or lived in a common law relationship. In total, 11 of 17 participants graduated from secondary school. Of the 11
participants who graduated from secondary school, 7 participants also had a diploma or completed some college or university courses. Two participants had graduate degrees and one participant had a bachelor’s degree and was working on completing a graduate degree. One participant was employed full-time outside the home, while six participants were employed part-time outside the home. Three participants were part-time students at the time of the first interview; two of them indicated throughout the course of the research that they had to quit or delay their studies. Three participants indicated that they volunteered in their communities. Seven participants were not employed outside the home. Of those participants, five indicated that they were receiving “welfare,” “income assistance,” or “disability payments.” Four participants indicated that they accessed the food bank to provide food for their families.

The average age of the school-aged children with FASD was 9 years (range 6 to 12 years). All of the parents indicated that their children were affected by prenatal exposure to alcohol to the best of their knowledge. Nine of the school-aged children had a formal diagnosis of FAS. Seven of the children had no siblings. Ten children had siblings living with them in the home (range 1 to 5); the average number of siblings was 2.3.

5.3 The Core Category: Intertwining to Fit In

The core category explains how caregivers come together with their children through intertwining; they use the strategies of orchestrating schooling and keeping up appearances to maintain their relationships with their children (intertwine) and engage with the school system in ways that permit them to be more “like” other parents (fitting in) and their children to be fitting in with academic expectations and other children. Regulating their relationships
with their children is intrinsic to intertwining to fit in and is used by caregivers to maintain their “parental” relationships with their children but avoid becoming intertwined to the point where they deny opportunities for their children to have the independence to fit in. Each of the two main strategies is comprised of tactics and sub-tactics that help parents and their children stay intertwined to fit in and regulate their relationships with their children so that parents can try to maintain “themselves” in the context of their relationships. The coming together with their children (intertwining), in ways that permit them to be “like” other parents and their children “like” other students, involves their constant management of dynamic tensions between being too intertwined or not intertwined enough. They are focusing their energy and time on their relationships with their children (especially when tactics to orchestrate schooling are unsuccessful and their children risk their placement at school or are not attending school), and also on their relationships with school personnel. Using the strategies successfully reduced the amount of time parents spent regulating their relationships with their children, permitted children more independence and allowed parents to direct more of their energy towards keeping up appearances in other areas of their lives.

None of the actions parents take occur in a vacuum. Conditions, such as availability of support, openness of school personnel to parents as experts on their children, living in poverty, and living with stigma, can influence caregivers’ attempts to intertwine to fit in. They have to throttle tactics up or down and direct more or less energy towards regulating the relationship with their children to stay intertwined in ways that permit them and their children to fit in. Because school conditions and children’s conditions change continually, caregivers are engaging and re-engaging in orchestrating schooling and keeping up
appearances to go through cycles of intertwining to fit in. Figure 5.1 presents an overview of
the core category.

Figure 5.1: Intertwining to Fit In
Orchestrating schooling is one of the strategies caregivers use to intertwine to fit in. The caregivers orchestrate schooling because they are trying to help their children succeed academically and in social interactions (fit in with other children and academic expectations). Staying intertwined with their children is partially reliant on orchestrating schooling because, if children are having difficulty with academic requirements or being shunned by other children, caregivers have to put more energy into orchestrating schooling and regulating their relationships with their children, which makes staying intertwined more difficult.

Conditions, such as modifications in school environments, influence the energy and time caregivers have to devote to tactics to support their children at school and in social interactions. Devoting extensive energy and time to promote children’s academic and social success (orchestrating schooling) either increases (hitting rock bottom) or decreases (reaching islands of calm) the time and energy caregivers devote to regulating their relationships with children to stay intertwined. Educational environments that are inflexible increase efforts to actively orchestrate schooling.

I think that the education system, the way it’s set up, it is geared toward normal, average children. And I think it’s also based on almost an industrial model, almost like a car plant where you send them in, and then you fit this on to them, and then you push them down the conveyor belt and put a bunch of other things onto them. And it’s geared toward conformity, really. And for a child who doesn’t know how to do that, or isn’t capable of doing that, then education becomes really, really challenging…. the ….challenge is to find a place where he is wanted and will be treated kind of respectfully and taught (17.1, lines 25-32).
Caregivers use keeping up appearances as a strategy to deal with one of their major concerns, which is that they will be regarded as “bad” parents. They use tactics to keep up appearances so they can fit in with other parents and stay intertwined with their children. They need some successes in their efforts to be seen as “good” parents so they can maintain the energy, time, and commitment to stay intertwined with their children through regulating their relationships. Putting strings of success (islands of calm) together contributes to their desired long-term outcomes which include happiness, stability and success for their children, and happiness, connection, recognition as a parent and self-actualization for themselves. Working towards those desired outcomes enables them to have the energy and time to regulate their relationships with their children.

Living in supportive neighbourhoods and living in poverty and with stigma are just some of the conditions that influence the amount of energy caregivers have available to direct towards staying intertwined with their children. If they are using a lot of energy and time to promote themselves as “good” or responsible parents by looking after basic needs, less time and energy is available for staying intertwined. A single father, who describes himself as “on Welfare, with $503 of support with two kids” describes his difficulties keeping up appearances at his child’s school:

Because the principal that was there [said], “the kids got dirty clothes.” But listen what happened that time, the laundry machine there, okay, upstairs, there was only one washer, two dryers for eighteen apartments. Now when you get family allowance you’ve got to be there early in the morning, because if you’re not you can’t wash your clothes. Now me, two kids, it gets piled up there and then okay I got… okay, like
Monday they sprayed my place there [for lice], three weeks in a row. I got still twelve loads of laundry to do. But the laundry room is always busy. Do it at the Laundromat, do you know how much it costs at the Laundromat? $1.50 to wash, $1.50 to dry (14.1, lines 620-629).

Caregivers’ efforts to keep up appearances are affected by the short-term outcomes from orchestrating schooling. It is difficult for them to use tactics to keep up appearances if, despite all of their tactics to orchestrate schooling, their children are not demonstrating signs of success academically or socially. Their children’s success reflects on their efforts to promote themselves as “good” parents. Outcomes from using tactics to keep up appearances affect how parents use tactics for orchestrating schooling because, if parents are being shunned by school personnel or left out communication and planning, they are more likely to hit rock bottom than to reach islands of calm.

Because conditions caregivers experience continually change caregivers are constantly engaging and re-engaging in strategies and tactics, throttling strategies up or throttling them down as needed, so that they can regulate their relationships with their children, stay intertwined and both fit in. In other words, they cycle in and out of the core category. As indicated in this quotation, there is never enough stability in the school system or their children’s interactions with the school system for caregivers to occupy islands of calm for extensive periods of time.

Well the difference from one year to the next is the people that you interact with during that year. So that for example in Kindergarten, that was sort of a… not a very good year. And so the next year you go into the same thing, and this an even worse
year. So it’s like you’re going through almost like the same dynamics, in the same building, with largely the same children. The only difference is the adults. And the difference is the adult interaction. And then often his [assistant]… he didn’t have a firm SEA until probably around December sometimes. Or he had someone who kept changing, and then rather than helping it’s more babysitting. And so you’ve got those kinds of variations (17.1, lines 1026-1036).

The amount of energy and time caregivers devote to regulating their relationships with their children in intertwining changes constantly depending on conditions and whether their efforts to orchestrate schooling and keep up appearances are working. There are cycles where intertwining to fit in is easier and caregivers and their children are more comfortably intertwined and moving toward their long-term outcomes; there are also cycles where intertwining to fit in is more difficult with too much or too little distance between caregivers and their children. In cycles where caregivers have to spend more energy and time on orchestrating schooling so they and their children can stay intertwined to fit in, they also have to expend time and energy regulating their relationships. Consequently, they have less time and energy to spend on keeping up appearances. Short-term outcomes from using the strategies to intertwine to fit in are interconnected. Short-term outcomes from both orchestrating schooling and keeping up appearances affect the tactics and short-term outcomes associated with the other strategy. When caregivers are not succeeding with orchestrating schooling they hit rock bottom. When they hit rock bottom, with none of their tactics working to help their children succeed at school, they cannot keep up appearances in the eyes of the school system. Thus, hitting rock bottom, with the negative short-term
outcomes, undermines caregivers’ strategies, puts their relationships with their children in jeopardy, and threatens their long-term outcomes.

But at the same time [through being at the school] trying to help him to be there and to fit in. And so, I mean, there’s no way that anyone could say that that piece hasn’t been there, ….that “his parents either don’t care or are too self-involved, or whatever” (17.1, lines 228-232).

The strategies for intertwining to fit in are complementary because aiming for success for their children helps caregivers to be regarded as “good” and responsible parents; being seen as “good” parents increases the likelihood their children will fit in at school and socially. Children do not fit in without the parents and the caregivers will not fit in as parents unless they can help their children fit in.

Hitting rock bottom undermines caregivers’ ideal outcomes of happiness, connection, recognition as a parent, and accomplishment other than parenting. Putting a lot of time and energy into keeping up their appearances makes it more difficult for caregivers to employ tactics to orchestrate schooling and promote academic and social success and happiness for their children. When caregivers reach islands of calm, with the short-term outcomes from orchestrating schooling reached, they can throttle down their efforts, enjoy respite, and feel good about themselves as parents. They have more energy available to devote to keeping up appearances. Caregivers feel they have reached islands of calm when their children are happy at school, stay in school, maintain their routines, show more mature behaviours, and feel included.
Regulating their relationships with their children is intrinsic to intertwining to fit in. Regulating their relationships is used by caregivers to maintain their “parental” relationships with their children but to avoid becoming intertwined to the point where they deny opportunities for their children to have the independence to fit in.

If caregivers are too intertwined neither they nor their children can sustain the level of involvement necessary to fit in (they are too close); however, if caregivers feel they cannot sustain their relationships and contemplate being un-entwined their relationships become too distant. There is the threat of loss of the relationship and an abandoning of their efforts to fit their children and themselves in. Thus, regulating their relationships with their children involves managing dynamic tensions between being too involved or too distant, without feeling they were abandoning or smothering their children.

And I felt very strongly that I needed to be present in the school, since I could not rely on my son to let me know what was going on, my presence in the school would at least provide him with some sense of being safe and of being protected (17.1, lines 120-124).

For caregivers of children with FASD, intertwining to fit in with their children means not only being constantly aware of how their children are doing and behaving but also vigilant about how they are perceived by others. Caregivers constantly observe their children, observe others to determine how they are perceived as parents, make sense of these observations, and re-direct their actions towards tactics to orchestrate schooling and/or keep up appearances to make sure they and their children stay intertwined to fit in.
The constantly changing educational environment, where school staff change, policies are implemented differently for different students, and the allocation of supports changes from year to year, influences children’s behaviour. Under those conditions, caregivers constantly adjust the energy and time they put into regulating their relationships with their children to make sure they continue to stay intertwined to fit in. There are cycles where caregivers manage to move into times of respite where intertwining is more comfortable (reaching islands of calm). There are also cycles where caregivers have to increase tactics to orchestrate schooling because their children are not finding academic and social success which puts keeping up appearances in jeopardy (hitting rock bottom). Increasing the time and energy directed towards orchestrating their children’s schooling drains energy and comes at a cost to other aspects of a caregiver’s self.

I have run out lately and find myself just fighting the battles for [my child] and putting me aside, I know, I know, without me she will not thrive but I have been doing this many years and it’s brick wall after brick wall… and you run out of steam ya know (5.1, e-mail correspondence).

Caregivers refer to children’s difficulties with emotion regulation, eating, sleeping, adapting to changes, and sensory hypersensitivity; all of those indicators of children’s behaviour influence how much caregivers need to regulate their relationships so they and their children can fit in. All caregivers closely observe their children for changes in behaviour that signal when they have to throttle up tactics and adjust the strategies, orchestrating schooling and keeping up appearances, which support intertwining so they and their children can fit in. Being constantly alert for changes in their children’s behaviour, part
of regulating their relationships, drains their energy over time, especially when caregivers encounter negative reactions to their attempts to fit their children in and to fit in as parents. A foster mother remarked:

So it’s what… it’s the common thread that I see with all of us that are caregivers, in whatever capacity for kids with FASD, is that our energy is so depleted. We’ve got this whole other package of advocacy and support and fighting tooth and nail for services that are so selective and so bizarrely… the criteria is so bizarre to be facilitated into the support services. Like you know, how can I even do that? (16.1, lines 1247-1254).

Caregivers also regulate their relationships through shifting their expectations about what constitutes success for their children and their expectations for success for themselves as parents. They increase their vigilance in response to any changes they are observing in their children’s behaviour so they can figure out how much time and energy they need to put into the relationship.

Shifting expectations is about lowering their expectations for short-term success so parents do not give up. When caregivers shift their expectations around school attendance (part-time rather than full-time) or what they expect their children to learn in school they can continue devoting time and energy to regulating their relationships and using their tactics because there is less resistance from their children.

That’s when I quit fighting with him. If I can get him up and get him to school without a lot of stress on either me or him, he goes. I don’t fight him anymore. It’s not worth it, and it was causing me to not feel good, it was causing stress in my life,
and I don’t need that on my heart. And it’s causing stress in him, he’s a very gentle person. … When I stopped fighting with him about going to school and fighting him about everything, it’s been a lot better (7.1, lines 263-274).

Hitting rock bottom means the strategies of orchestrating schooling and keeping up appearances in the context of the school system are not working. When caregivers reach a critical juncture of hitting rock bottom they withdraw from using the strategies to fit their children in the school system and to fit in as parents so they can stay intertwined. The caregivers indicate they disengage from others, feel exhausted, angry, and drained, and, in some cases, guilt and grief. Hitting rock bottom requires caregivers to devote more time and energy to regulating their relationships with their children. Conditions, such as the availability and accessibility of supports or living in a close-knit neighbourhood, affect the severity of hitting rock bottom and how long it lasts. For a number of caregivers hitting rock bottom put intertwining (their relationships with their children) under threat:

And at one point I was so frustrated and so in my own guilt and whatever, I said maybe I need to give her up…. I mean I couldn’t, but out of sheer desperation I was ready to go, “I can’t do it. (5.1, lines 213-221).

On the other hand, reaching islands of calm is a critical juncture with caregivers moving into times of respite, tranquility, getting support, and feeling hope so that intertwining to fit in is easier. Reaching islands of calm provides caregivers with evidence of their success in orchestrating schooling which has positive effects on keeping up appearances because their children’s success reflects well on their parenting capacities. On islands of calm,
relationships with children are on a firmer footing, which requires less time and energy being spent on regulating relationships and more time for caregivers to develop accomplishments in other aspects of their lives.

Islands of calm represent periods when children are happy going to school, feeling included, staying in school, behaving more maturely, and keeping to their routines. Because children are perceived as fitting in, caregivers can throttle down tactics and scale down attempts to keep up appearances at their children’s schools. They can direct more of their energy into keeping up appearances in other parts of their lives through socializing, working, volunteering and hobbies. For biological mothers, islands of calm are times where guilt associated with the affected child is less prominent. Unfortunately, islands of calm do not persist because children and schools are constantly changing and caregivers are dealing with loss of stability.

Caregivers move out of rock bottom or from islands of calm towards increased efforts to orchestrate schooling and keep up appearances by re-engaging with the school system. They advocate, educate, and change settings. If the re-engaging is successful, they return to orchestrating schooling and keeping up appearances at their child’s school and in the neighbourhoods where they live.

I’ve talked to them and I said, “My little one has FASD and I said there’s stuff you have to understand about her…that there’s things you might tell her and it goes over her head and she’ll ask you again” and I said “I don’t want you to think she’s dumb or stupid or lazy…I said she has a disease…FASD…and she might be slower to pick up stuff and that you might have to repeat it to her…you know” (3.1, lines 251-256).
Caregivers’ success at employing strategies to intertwin with their children to fit in, affects their long-term outcomes. Caregivers enter cycles, from hitting rock bottom or reaching islands of calm, depending on whether they are successful or unsuccessful at short-term outcomes. When islands of calm are strung together for longer periods of time through persistent caregiver actions and favourable conditions, caregivers have a sense that they are cycling forward towards their ideal long-term outcomes for themselves and their children. For children, ideal long-term outcomes include social and academic success, happiness, independence, and stability. For caregivers, ideal long-term outcomes include happiness, hopefulness, connection, recognition as a good parent, and actualization in areas other than parenting.

If, after many cycles, the ideal long-term outcomes associated with the core category are not achieved, there is a sense that caregivers are cycling backwards or losing ground. For children, academic and social success and independence are threatened. Caregivers can feel their sense of self-identity beyond parenting slipping away, as well as their sense of connectedness and of being a good parent. If they cycle back to the point of hitting rock bottom they experience exhaustion, can be excluded or shunned by others, disconnect from others, and feel unacceptable as parents. In those situations, the negative outcomes associated with rock bottom become more pronounced and there is danger of ruptures in their relationships, which threaten intertwining to fit in. In the next two sections of the chapter, I describe the main concerns and long-term outcomes, including the ideal outcomes caregivers are striving for.
5.4 The Main Concerns

The main problems participants are “trying to manage” are preventing their children from failing academically and in social interactions and, preventing themselves from being regarded as “bad” parents. Caregivers continuously and simultaneously try to resolve or process the main concerns for their children as well as the concerns for themselves.

It doesn’t really matter what it is, you’ve always got the aftermath…., in addition to trying to navigate through as a parent, in hopes of it making it better for the child (16.1, lines 108-116).

All caregivers clearly articulated their main concerns for their children. They describe their children as “failing” at school when they observe them to be not teachable, not attending school properly, not able to take in information, not getting along with others, not making progress, and not keeping their behavioural difficulties less evident.

The main concerns caregivers tried to process for themselves were developed over time through constant comparison of data from interview transcripts, fieldnotes and documents. My constant comparisons indicated that when caregivers perceive their children to be failing, their attempts to prevent themselves from being regarded as “bad” parents are undermined. They feel that they are not accepted as parents and are blamed for what is happening to their children. They see themselves as different from other parents and as not appearing “responsible and good.” A caregiver who described her interactions with school personnel and perceived her child to be failing academically and in social interactions, said: “I can’t give her what she needs.” What does that make me feel like?” (5.1, lines 221-222).
Through a pattern of behaviour, intertwining to fit in, caregivers attempt to resolve their main concerns and strive towards ideal long-term outcomes for themselves and their children. The long-term outcomes are described in the next section.

5.5 Long-Term Outcomes

To respond to their main concerns, caregivers strive for particular positive long-term outcomes or ideal outcomes. When strategies are successful, caregivers perceive them and their children to be moving closer to positive long-term outcomes. High demands on energy and time with no opportunities to meet caregivers’ long-term ideal outcomes can lead to caregivers contemplating being un-entwined from their children, a negative long-term outcome.

For children, ideal long-term outcomes include academic and social success, happiness, independence, and stability. For caregivers, ideal long-term outcomes include being connected, recognition as a parent, happiness, and a sense of self-actualization or accomplishment beyond the parental identity. A parent expresses the common need of all caregivers interviewed to be affirmed as a good parent by others: “It’s amazing how…every parent needs that. They need somebody in their corner, going ‘you’re doing a good job.’ …. That’s just so important” (9.1, lines 253-258).

Caregivers define academic and social success for their children as “being the best that they can be.” Participants want their children to read, know “some” math, have life skills, complete their grades and graduate. Social success includes children belonging and developing long-term friendships with peers. Their children feel “wanted and welcome,” “they belong,” “comfortable,” “the same,” “emotionally safe,” “respected,” “a part of.”
Rather than focusing on any positive peer relationship, the caregivers were looking at belonging in the context of the school system. Caregivers’ definitions for success for children also include stability and independence. When intertwining to fit in through strategies (orchestrating schooling and keeping up appearances) is successful, children are more likely to attend school and stay in the same school or program over the long-term. Because parents do not have to intervene when children are successful in school, caregivers see their children as more independent which makes them feel like they are moving their children forward.

When long-term outcomes of success are achieved by their children, caregivers can claim substantial evidence supporting their status as “good” parents. They can be viewed in “the eyes of the authorities,” particularly school personnel, as good and responsible parents. Beyond being seen as “good and responsible parents,” caregivers’ long-term ideal outcomes are to be connected with other parents, feel happy and hopeful, obtain a sense of identity from hobbies or paid work or volunteering, and feel that they are more like other parents. The two sets of long-term outcomes are intertwined. Parents cannot fit in without children fitting in and children have difficulty fitting in if parents do not fit in. When children are happy and successful in school caregivers are “feeling good about themselves as a parent,” “feeling comfortable with themselves as a parent,” “and “feeling good about supporting their child.” They feel like responsible parents because they feel they do “what a parent is supposed to do.”

And the more I do, the better I feel about the safety network for my children to make sure that they’re learning, that they’re okay, they’re happy, they’re adjusted to what’s
happening and asking them, too, if they like it. “What do you like about it? It’s fun, Mom. I’m learning” (1.1, lines 741-745).

For biological parents, an additional element of success is the sense that they have made up for past mistakes through moving their children forward. When intertwining to fit in leads to success for children biological parents can reinvest in hope for the future:

If she feels included and has a good time, then she’ll feel more inclined to venture forward and, you know, maybe try other things…if you don’t have other successes it makes it very hard to want to jump in (5.1., document analysis).

Notwithstanding many caregivers’ views that they will likely have to orchestrate schooling for their children or keep up appearances for themselves for what feels like forever, seeing their children staying in school, possibly graduating and being more independent allows caregivers to be more hopeful about their children’s futures and to feel like good and responsible parents. For biological parents, there is a sense that the cycle of addiction in their families may be broken.

I wish there was more…as I was growing up I wished there was something for me. Yeah…like my parents didn’t know. Of course my Mom must have did this or that but didn’t know there were supports out there. Where I broke the ice and here I am…parenting my children and it’s hard…it is hard (1.1, lines 1174-1179).

In part, through the pattern of behaviour, intertwining to fit in, caregivers find their happiness and a sense of accomplishment in seeing their children succeed academically and in their relationships with peers:
I’m so proud of her…she’s learning her multiplications and she wants me to teach her how to do the…division (3.1, lines 260-261).

Successful and happy children increase caregivers’ positive feelings about themselves as parents. Realistically, having caregivers articulate their ideal long-term outcomes as success, does not guarantee their strategies will be successful for their children. Their children may not fit in.

Who wants to do something they fail at? That is what ends up happening, and it gets really disheartening because all she wants to do is fit in (5.1, document analysis)

Being unable to achieve even short-term successes or constantly hitting rock bottom, with children and caregivers having great difficulty with the process of intertwining to fit in, requires caregivers to invest extensive energy and time in regulating relationships with their children. Investing energy and time, but not moving towards long-term ideal outcomes can lead to caregivers contemplating being un-entwined from their children:

I have my moments where I just wallow away in my guilt and lose my mind, kind of thing, and I’m useless. And those are the days I go, maybe I just got to give her up, because I can’t do this. (5.1, line 362)

Using theoretical sampling, I was able to access one caregiver who became un-entwined, or made the decision to give up on the caregiving relationship when, under conditions of limited support, she repeatedly failed to meet the outcomes she was striving for. Although potentially moving back in to the caregiver relationship with her child, she was not yet actively
orchestrating her child’s schooling. As a result, she was concerned about preventing being perceived as an uninvolved and uncaring parent:

And the group home is like ‘We’ll take care of everything.’ Cause they want to take care of everything…. They’re going to go get him [from school]…. I told them I have no problem in picking him up…. but they said they will (13.1, lines 277-288).

All of my participants reached short-term outcomes (articulated in hitting rock bottom versus reaching islands of calm) resulting from their efforts to orchestrate their children’s schooling, in the context of FASD, through intertwining to fit in for children. A system that is constantly changing and unresponsive to children’s challenges creates conditions that increase the likelihood caregivers will move toward hitting rock bottom. Over time, when none of the ideal outcomes caregivers are striving for are reached and many instances of hitting rock bottom occur, rather than reaching islands of calm, caregivers regard themselves as cycling backwards:

I guess my personal philosophy is if you’re not moving forward you’re actually going backwards. So I think without there being some sense of moving forward then we’re in trouble I guess, really….either in trouble or we’re going backwards (16.1, lines 834-838).

Caregivers indicate their sacrifices of their ideal long-term outcomes, being connected with other parents, feeling happy and hopeful, obtaining a sense of identity from hobbies or paid work or volunteering, and feeling like they are more like other parents, can be tolerated more easily when their children are succeeding. When their children experience unhappiness and
instability, caregivers feel badly about themselves as parents and guilty. Under those circumstances they can cut themselves off from others, including their children.

To summarize, long-term outcomes caregivers are attempting to achieve for their children include success at school and social relationships, happiness, independence, and stability. All of these outcomes require extensive periods of calm, without major disruptions to children’s lives. That means that caregivers, in spite of achieving some islands of calm, constantly have to re-enter the cycle of intertwining to fit in to achieve the short-term outcomes every step of the way, outcomes which provide hope over the longer term. For parents, the only route to being connected, maintaining recognition as a parent, feeling happiness, and achieving a sense of self-actualization or accomplishment beyond the parental identity is through continuing to enter the cycle of intertwining to fit in and using the strategies over and over again. That enables them to stay in their relationships with their children without spending all of their time regulating them. If there are no signs of success and hitting rock bottom goes on and on or is almost constant, caregivers either contemplate leaving or leave their relationships with their children. In the next two sections of the chapter, I explain in detail, the strategies caregivers use, beginning with orchestrating schooling.

5.6 Orchestrating Schooling

Orchestrating schooling involves conscious actions caregivers take to promote their children’s academic success and success in social interactions (help them to fit in), while staying intertwined with their children. Caregivers perceive tactics for orchestrating schooling to be working and themselves and their children fitting in when they see their children making academic progress, attending school, keeping to their routine, making
friends and enjoying school. The kinds of outcomes caregivers are ultimately seeking for their children where they belong and function positively with peers, are captured by the following quotation from an adoptive mother:

If you don’t fit in, if you don’t belong, not only don’t fit in but you aren’t allowed to fit in, you aren’t allowed to belong, you aren’t allowed to function in a positive way, then what’s left for you? (17.1, lines 396-399).

Orchestrating schooling is comprised of four tactics that help caregivers and their children succeed in school and social relationships so caregivers and children can stay intertwined to fit in, while caregivers are trying to keep up appearances and maintain “self” in the context of their relationships. The tactics are being on stand-by, pitbulling, cultivating connections, and anticipating difficulties. Figure 5.2 provides a visual image of the strategy, orchestrating schooling, with the associated tactics.
Orchestrating their children’s schooling is active, hands-on, and time consuming for caregivers. When tactics for orchestrating schooling are not working, or when children enter a new grade, school, or relationship with a teacher, caregivers have to redouble their efforts and escalate to 24/7. Twenty-four/seven indicates they are spending all of their time on
stand-by without any respite, which reduces their time and energy for social relationships, paid employment, volunteering in their communities, and engaging in hobbies. Unsuccessful tactics for orchestrating schooling require them to intensify their strategies to fit in as parents and abandon any other activities. The time-consuming nature of orchestrating their children’s schooling is reflected in the paid employment status of the participants. One participant was employed full-time, while six participants were employed part-time outside the home. The participant who worked full time had a partner who worked flexible hours. She indicated that they always had one parent at home, in case they got called to the school. Four of the participants who worked part-time indicated that they either declined a promotion or reduced their working hours because of the full time nature of managing their children’s schooling.

Three participants were part-time students at the time of the first interview; two of them during the course of the research had to quit or delay their studies. Seven participants were not employed outside the home. A participant, who describes being called in by the school during cycles where her child’s behavioural difficulties escalated, describes the effects of orchestrating schooling on her ability to work:

I was offered a promotion and I had to turn it down. I have to work as part time as possible, but hold onto my benefits because the medication he’s on is so expensive (7.1, lines 69-71).

A participant who was previously employed indicates that she had to give up previous paid positions as a result of the time commitment needed to manage her child’s schooling:

I have to advocate so strongly for him at the school level that I have to give up work basically to get his needs met.…I had a business…a flourishing business before I had
[him] and the business is now gone because that become my priority…right (4.1, lines 862-871).

When caregivers perceive their children to be failing in school they also perceive themselves to be failing as parents. In addition to throttling up tactics for orchestrating schooling, they also direct their focus to regulating their relationships to the point necessary to stay intertwined so both their children and they can fit in.

5.6.1 Being on Stand-By

All caregivers use being on stand-by to orchestrate their children’s schooling. Caregivers have to be ready to intervene to protect their children from fallout arising from frequent medical concerns and their children’s behaviour, which can jeopardize their ability to be successful at school. Parents used the tactic, being on stand-by, to parachute in to take their children out of school when they got into difficulty. Caregivers (who are not on stand-by) are aware their children may be asked to physically leave the school if they demonstrate escalating ‘bad’ behaviours. Being on stand-by involves “increasing time being present at the school” and “scaling down other activities.”

Child factors (i.e., the medical concerns and behaviours that result from prenatal exposure to alcohol) and school factors influence the amount of stand-by required, while caregiver factors (e.g., financial resources and relationship status) influence the ease or difficulty of being on stand-by. Child factors affect the amount of stand-by required for caregivers to orchestrate schooling so it does not fall apart and they can stay intertwined to fit in and maintain their relationships with their children. For many caregivers, regular trips to the physician or emergency ward of the hospital are part of their day-to-day lives. There is a
sense that they have to intervene quickly when they get called by the school. As one parent said: “when these children get sick, they get really sick.” Another caregiver reflects on the seriousness of her child’s medical condition which affects all aspects of her life with her son and necessitates her being on stand-by:

There’s a lot of coordinating services. [My son] has chronic health issues that are related to his [rare medical condition]. He has to have a growth hormone injection daily….his body can stop producing all sorts of hormones so he has to go annually for tests to make sure he’s still producing other chemicals because that could shut down at any time (4.1., lines 843-851).

For caregivers whose children experience frequent medical concerns associated with their exposure to alcohol, the intensity of being on stand-by is increased, which affects their ability to attend to self through working. Not working has implications for their efforts to be seen as “good parents” and have an identity beyond being a parent. A caregiver, whose child experienced frequent medical illnesses and mental health difficulties that became more evident over time, explains having to increase being on stand-by, which affects her abilities to find paid employment:

And of course her lates and absences last year, through the roof. Through the roof.

How am I supposed to look for a full-time job? I was getting called [by the school] in the middle of an interview. Who’s going to hire me? (5.1, lines 207-210).

The unpredictable nature of the behavioural difficulties associated with FASD increases the amount of stand-by time required. Having children “falling apart” can happen very fast
because children with FASD have difficulty with behavioural regulation, which includes rapid changes in mood. Children will go from happiness to sadness or anger, without warning. Caregivers indicate that their children have strong and unexpected reactions to stimuli in the environment. When triggers and responses are unpredictable it means caregiver intervention is “needed when it is needed.” That makes it difficult, if not impossible, to anticipate when children’s behaviour will jeopardize their efforts to fit in to the point where they have to physically leave the school. If children are asked to leave the school, caregivers must throttle up or put more energy into regulating their relationships with their children and intertwining with their children. In the following quotation, a biological mother explains being on stand-by as a result of the unpredictable nature of the behaviours associated with FASD, which jeopardizes her efforts to fit her child in, with the potential result of not being in the school:

   R: Okay. So that’s part of something that I’m very interested in, too, because parents have talked to me about it. You might have a different experience but I’ve had parents who’ve told me having a child with FASD in the school, means that you kind of have to be on stand-by all the time.

   P: All the time!.... 24/7!....That phone better be working and if you leave the house you better have a cell phone because if that kid has an episode at school, you’ve got to be there immediately (12.1, lines 287-298).

Caregivers throttle up being on stand-by depending on how evident their children’s behaviour and mental health difficulties become. When behavioural difficulties escalate to
the point where staying in the school is no longer an option, caregivers get called in to segregate their children:

I’ll get a phone call that he’s missing, and you’ll find him under a table somewhere because a situation happened, and with his level of anxiety he doesn’t have the skills to be able to go through the whole process of “stop, wait, what happened, I feel this way, this is what I’m going to do about it.” So that is a safety issue to them, so then we have to come and get him (7.1, lines 55- 61).

Taking their children out of school, through being on stand-by, prevents children from being excluded for longer periods of time which would undermine the long-term outcomes of success caregivers are striving for. Intervening when needed, through being on stand-by, also helps caregivers to be regarded as “good or responsible” parents. Where the school is unable to support children, through support workers or a lack of knowledge about FASD, caregivers have to increase the amount of stand-by time so they can be available at short notice:

P: They just… yeah, Kindergarten, of all things. I was in shock. I’d just finished dropping him off, and the vice-principal called me on my cell and told me, “You’ve got to come and pick him up now.” And I’m like, “I just dropped him off, he’s supposed to be in school.” “Well, he’s not listening, and he’s not doing this, and he won’t stop laughing at us, and he thinks everything’s funny, and we can’t deal with it, so you’ve got to come and get him” (15.1, lines 88-95).

Caregivers increase the amount of stand-by time by taking on volunteer positions at their children’s schools so that they are immediately available to intervene when their
children’s behaviours escalate. They volunteer for field trips, volunteer to be a playground supervisor, or help out in their children’s classrooms. Other caregivers linger around the school after drop-off time or stay in close proximity to the school just in case they need to go back in. An adoptive parent who turned down a promotion and works part-time so she can be on stand-by to reduce possible triggers that could jeopardize her child’s chances of fitting in said the following:

The other thing is the field trips, I want to be able to go on them because I know how many triggers can happen, something’s new to him, and as much preparing as you can do you can’t prepare him for everything all the time. So I like to be able to go on field trips and I let them know when I’m available so that I can do that. Three afternoons a week at least if they were to phone me, I’m home. That’s great, I can come get him, I can come (7.1., lines 76-82).

When caregivers scale down other activities in their lives to be on stand-by to support success for their children they do it at the cost of caring for self. Caregivers indicate they would prefer not to be on constant standby; therefore, they work hard on other tactics to support their children’s independence and stability, such as pitbulling and making connections. As one parent said: “It’s not that I really want to be on-call 24 hours, but where that helps the child is …the more consistency there is [through me being there], the less anxiety there is for her in the school environment” (16.1, lines 279-283).

Because children with FASD have difficulty adapting to frequent changes in the educational environment it also increase the amount of stand-by required of caregivers. Almost all participants refer to high support staff turn-over as interfering with their children’s
routines. During cycles characterized by frequent changes, caregivers increase their stand-by to be able to step in and monitor for indicators of behaviour that suggest worsening situations. Change may result from chance (e.g., when a teacher goes on maternity leave or gets sick) or from staff turn-over caused by union rules (e.g., an assistant leaves and gets replaced by the person with the most seniority). Seven caregivers have children in the 11 to 12 year old range. Most of these caregivers indicate that the school environment becomes more unpredictable for older students, necessitating them to increase the amount of stand-by required. One parent said: “Now the 11-year-old… is now in middle school so now he has six teachers…. and some of them are substitutes” (9.1, lines 200-202). Another caregiver said:

Well… I’m way more involved now… way more involved. As they got older I got more and more involved because there were more and more problems as far as the educational part of it went. Like the gap between what they can do and what the school would want them to do so I was more and more involved in more figuring out… (9.1, lines 117-122).

Caregivers sometimes contribute to staff turnover: When caregivers rely too heavily on teachers’ assistants to regulate their children’s behaviours the teacher assistants get burned out. One participant, an important negative case, indicated that a lack of staff turn-over could also make orchestrating children’s schooling more difficult. When support staff members are burned out they become less motivated to try their best to help children to fit in.

P: I found that after about two years people started becoming stale… no matter how skilled they were… the teaching assistants become stale. They’re not wanting to learn more.
R: Stale…what is stale?

P: Stale in the sense that “Oh well, they’re never going to learn that” or they’re not willing to look at different things or working around the challenges (4.1, lines 703-711).

There are also conditions that reduce the amount of stand-by required of caregivers. Less stand-by time is required when children receive extra assistance in school as a result of meeting their district’s criteria for extra support, and the assistant is knowledgeable about FASD and can structure the environment to prevent children’s secondary disabilities from escalating. Under those conditions, caregivers do not need to be ready to parachute in to take their children out of school at any moment. Because children appear more autonomous caregivers can temporarily throttle down their tactics to orchestrate schooling to support intertwining to fit in.

For caregivers without financial resources, being on constant stand-by is more difficult than it is for parents with financial resources. An unemployed biological mother explains how, faced with lack of understanding of FASD and a lack of resources from the school environment for her child, she increases her stand-by time to help alter the environment that triggers her child’s behaviour, thus, reducing her ability to engage in paid employment:

So they moved her again. She couldn’t handle the noise. None of the chairs and desks have rubber balls on. So that’s another quest I’m on is to find used tennis balls to donate, and I will sit there and I will cut them and I will put them on the desks myself
if it’s going to make my daughter’s life easier, I will do it, right. If I could afford to go out and buy them, I would, right, but again that’s time that I spend. Do I want to go to work and make money and be able to take her to Disneyland? Hell yes. But instead I have to keep managing all this stuff, right. So where do I find the time to find a full time job and find tennis balls to keep her in school? And if I don’t keep her in school, how can I get a full time job? (5.1, lines 256-258).

Cutting down on work to be on stand-by can jeopardize caregivers’ abilities to earn money to take care of their families and can make it more difficult to promote themselves as “good” or responsible parents. For single parents, stand-by time is more difficult. A single father describes how being on stand-by impacts his ability to find paid employment:

R: I’m hearing parents saying to me, “I would like to work, but I can’t because I have to be on stand-by because the school can call me any time.”

P: See, that’s the problem.

R: So can you tell me just a bit more about that, in your experience?

P: That’s the big problem being a single parent, man or woman. You can’t really have a steady job, or even a part time job. Like I said [my son], the two first years there I’d be there at least twelve to fifteen times out of the month to take him out of the classroom because he’s not behaving, he can’t handle it. The school or the special class, the one teacher would call and then tell me, “Well, he is having a real bad day today. Can you come and pick him up?” Now me, if I’d had a job, if I’ve got to do
that like I said fifteen times out of thirty days, my boss is just going to look at me,

“Okay, you want your job or you…” So I’m stuck right now (14.1, lines 43-57).

Having a partner who is employed may soften the financial impact of orchestrating schooling through being on stand-by, however, there is a sense that one parent takes most of the responsibility of orchestrating for success for the child:

R: So, being in a relationship is helpful when you’re a parent of a child with FASD?

P: Yeah. It can be…but it can also be a lot harder because like I said, if the other parent doesn’t understand, sometimes it’s just easier that you do it on your own (12.2, 780-784).

Even when caregivers’ work environments are flexible so they can be on stand-by and maintain a paid position there are financial implications. Consider the following description of the consequences of being on stand-by, given by one of the few participants able to keep a job:

Your son did this. Is there any way [you can pick him up?]…. I’ve lucked out…I have a boss that understands that I have problems with my children and that there are other people at my work that can cover my shift. I lose out on money all the time (12.1, lines 313-316).

Being on constant stand-by also affects caregivers’ mental well-being. Under conditions where children’s behaviours escalate or become more evident because of a lack of adequate support in the school system, caregivers experience stress which impacts all aspects of their
lives and well-being. A caregiver indicated she had to “quit for stress, because [she] was always at the school” (13.1, lines 30-35).

When caregivers unsuccessfully use the tactic of being on stand-by, they have to engage in other tactics to orchestrate schooling and stay intertwined to fit in, or hit rock bottom where successful outcomes for their children and themselves are undermined. As indicated in the above quotation attending to other aspects of “self,” in this case through being gainfully employed, is also undermined.

5.6.2 Pitbulling

Caregivers also used the tactic pitbulling to orchestrate their children’s schooling. They described pitbulling as daily battles focused on managing their children’s schooling. I identified sub-tactics of pitbulling, namely standing firm and hauling in support, and identified conditions under which caregivers moderated their pitbulling actions by treading carefully. Caregivers carefully considered directing their time and energy towards standing firm, hauling in support, or treading carefully. Parents considered not only how their actions could contribute to success for their children, but also how their actions could potentially influence parents’ standing in the school system. Conditions, such as the availability of support, also influence how caregivers direct their actions and the kinds of pitbulling tactics they use.

When caregivers pitbull, they battle for the kinds of environmental conditions that would enable children to regulate their own behaviours, for others to understand their children, and for support for their children. When they were pitbulling they were considering what they believed their children required to meet their educational and mental health needs.
Pitbulling captures the tenacious quality of caregivers’ interactions with school personnel. Caregivers try to ensure children get support and understanding, even when the school personnel view those elements as unnecessary or impossible. They push until they get what they believe their children need, keeping at it “even when it kills to do it,” and not accepting no for an answer. Through pitbulling, caregivers push back against conditions that make it more difficult for both themselves and their children to intertwine so that they can fit in. Battling for their children also helps them promote themselves as “good” or responsible parents. A caregiver explains pitbulling as follows:

Don’t give up. Refuse to take “no” for an answer. Keep going until you can find someone that will help you. Because that’s what I do, right. They’re strapped budget-wise, I get that. There’s only so much they can do, right. But if you don’t do it then the child then feels you don’t care about them (5.1, lines 583-587).

Standing firm happens when caregivers do not back down. They fight for what they believe is essential. In a sense, they put to one side their fears about negative reactions to them from school personnel. When they observe their children failing to fit in at school and to experience success, their fears for their children’s immediate and long-term well-being take centre stage. Standing firm takes a toll on caregivers because the tactic involves taking a stand against the school system and constantly seeking resources and support. At the same time, their children might be in a holding pattern at school where they are not fitting in, which means caregivers also have to direct more energy towards regulating the relationships with their children. Caregivers describe standing firm as going up against “red tape and rhetoric,” and “me against them.” Essentially, the time and energy involved in standing firm
and regulating the relationships with their children prevent caregivers from attending to other parts of their lives. The following quotation illustrates standing firm under conditions where an adoptive mother observes her child to be losing her identity:

But when your child is isolated and isn’t allowed to play with the other children, and isn’t even allowed to use the same washroom as the other children, then the idea of minding your p’s and q’s and walking on egg-shells disappears. Because you are in a position where you either make a stand, or else your child is washed away (17.1, lines 186-190).

Caregivers who perceive themselves as the kind of person that can stand firm and/or are knowledgeable about FASD are more likely to use standing firm as a tactic. Those who do not feel they can stand firm and/or are not as knowledgeable about FASD are more likely to use hauling in support from the “outside,” provided that support is available.

When caregivers haul in support they involve others outside their children’s schools to serve as allies in orchestrating their children’s schooling to achieve success. Hauling in support helps caregivers avoid possible negative outcomes for themselves and their children; negative outcomes may arise when standing firm does not result in the kinds of school environments that would allow children to be more independent. Hauling in support was related to the level of resources caregivers had or how connected caregivers were to their community, or both. Outside support may be support from the district level (e.g. behavioural consultants), the provincial level (e.g. provincial consultants), the medical system (e.g. the child’s psychiatrist), key workers, or their communities. Caregivers can also use hauling in support as a tactic when they try standing firm and it does not work. Some caregivers decide
to haul in support even when they perceive themselves to be knowledgeable and able to stand firm. As one caregiver said, “It can be very intimidating to walk in and there might be fifteen of them and one of you, and it’s on their turf at their time” (8.1, lines 110-112). Because hauling in support takes time and planning caregivers are more likely to stand firm when the stakes are high and reaching their ideal outcomes are threatened; they are more likely to haul in support when the situations with their children’s schools are not posing such a dire threat to ideal outcomes.

Hauling in support can be related to the level of resources caregivers have or how connected caregivers are to their community, or both. For caregivers living in a close-knit neighbourhood who are connected to their communities, hauling in support is easier because they perceive criteria for accessing support to be flexible in their community; they also have more long-term supportive connections to haul in to make pitbulling easier. For caregivers who are insiders to the educational or health care system, hauling in support is easier because they have knowledge about how to navigate different layers of the system to get support. When support is not available or caregivers do not perceive support to be meaningful, caregivers are more likely to use standing firm to stay intertwined to fit in.

Pitbulling also affects caregivers’ attempts to promote themselves as “good” or responsible parents. Influences from school environments can increase the work required by caregivers to stand firm or haul in support. These can include teachers lacking information about how to best structure the classroom environment to maximize children’s chances for success or lack of sufficient resources in schools to support children’s success, in particular teaching support workers. A caregiver who hauled in support from the district administrator describes the environmental conditions that influenced her actions:
Come this year that SEA was put in the classroom to support their child, my child, plus three other students that get some resource support…I was concerned because my son’s supposed to get full-time support and there is only one person in the classroom, so how is it going to work? (4.1, lines 66-71).

In the absence of help from the school, children’s behavioural difficulties become more pronounced; caregivers have to direct more time and energy towards regulating the relationship with their children through increasing their vigilance about changes they are observing in their children’s behaviour and shifting their expectations about short-term outcomes of success so they can stay intertwined to fit in. Whether children have received a diagnosis influences the educational environment and affects caregivers’ efforts to stand firm. Children who have not yet received a formal diagnosis, which would increase their likelihood of a designation as a child with special needs and supports being allocated by the school, require caregivers to increase their efforts to stand firm so success for their children and for them as a parent can be more likely. Without an assessment to back them up in their battle for support, caregivers find standing firm is more difficult. The assessment process can also help caregivers connect to some supports, which makes hauling in support easier. The converse situation with no diagnosis and no access to support undermines caregivers’ use of pitbulling. A foster mother described how not having had an assessment for her child made her efforts to pitbull more difficult:

Oh, and part of the dilemma at that point was we did not have a diagnosis. So all we were dealing with was all of her other issues, there’s lots of them. You know, PTSD, OCD, ODD, possible ADHD. The standard throw it all on one plate. Although I had
felt from the very first time when I got her, I felt that there probably was some level of brain damage but that’s based on my experiences. So that was part of the dilemma was not having the fancy piece of paper that would allow or enable them to do anything other than what they were doing, which is a system failure (16.2, lines 620-626).

This caregiver also feels disregarded as a parent when, in the absence of having a “fancy piece of paper” or an assessment report, her input, in the form of standing firm, is not enough to influence the educational environment for her daughter. When caregivers’ use of tactics, like pitbulling, is undermined by educators, keeping up appearances and intertwining to fit in become more difficult.

Helpful key workers can supplement caregivers’ knowledge so that they feel comfortable using them as a proxy or an ally in terms of standing firm for their children. Participants define helpful key workers as being knowledgeable about FASD, individualizing support provided to caregivers and their children, maintaining a trusting relationship, and being available immediately, or on a “9-1-1” basis when help is needed. Consider the following description from a caregiver who hauled in a key worker from her community to supplement her knowledge and be an ally to battle for support and understanding for her child:

R: How does it help to take someone to a school based meeting?
P: Because sometimes I do not understand, and I look at her right away, and … then she knows and then she explains it to me later, or right there. And yeah, so I do find that it’s better to have somebody there with me (15.1, lines 203-209).

Unhelpful key workers take a “brokerage and linkage approach,” by going through the motions of passing on information to caregivers; failing to invest in relationships with caregivers; requiring appointments to meet with caregivers; or breaking down trust with caregivers. Under those conditions, caregivers are less likely to haul key workers in for support. Lack of consistency in training is viewed by caregivers as producing unhelpful key workers. A biological mother described her perception of key worker training and her distancing from her key worker:

Key workers, like I said, they were originally trained by [name of trainer], they all knew what it was about. Then the government decided they don’t want to pay [name of trainer] to do this anymore, in their infinite wisdom. Key workers can now train other people to be key workers. So whatever part of the training you heard, you showed up for, you got, you liked, you chose to practice, or had the money in your agency to do that part would be what you taught. Now you have a bunch of key workers, there’s no consistency, there’s no set of standards other than whatever they’ve been told they can do. (laughing). How is that helpful to me? (5.1, lines 1270-1286).

In particular, if caregivers perceive key workers as threats to their ability to stay intertwined with their children (e.g., key workers may report conditions in the caregivers’
home environment to social services), they view them as unhelpful. The following example illustrates a situation where trust breaks down when a biological parent responds to a threat to label her as a bad or irresponsible parent, putting her relationships with her child in jeopardy:

So the key worker had mentioned “Well, you know Child Care Protection might need to be called in.” I freaked! I freaked! …. After all I go through to…to advocate for her…to support her…to find resources…all the stuff I do and you’re going to report me because I have boxes. “Well…you know visually stimulating environments aren’t good for children with FASD and you of all people should know and you’ve been in a documentary and you go to conferences and you have a website and you…you…you…” About me right. And it was like she was attacking me and I was just like…you’re supposed to support me (5.2, lines 65-74).

Caregivers have to dial down their pitbulling and focus more on how they come across as parents when they are worried about jeopardizing their relationships with teachers and other staff and about undermining their efforts to help their children achieve success and intertwine to fit in. To dial down pitbulling or tread carefully, caregivers pull back and analyze their acts and the anticipated outcomes of their acts on others. They reduce the level of standing firm and feed that back in. There is a fine line between pitbulling and being seen as a “problem parent,” which makes it more difficult for caregivers to keep up appearances and stay intertwined with their children. In the following quotation, treading carefully enables this caregiver to be viewed favourably by the school:
Well it made me realize very quickly that I had almost a full-time advocacy role, which was really not what I had hoped for. And in many ways, I suppose, it put me in the position, at least I felt, of being kind of the parent who everybody walks on their tippy toes …. as soon as I’m around. And so I try very much to counterbalance that ….(17.1., lines 115-120).

Being an insider to the education system made it more likely that caregivers would moderate pitbulling. The four caregivers who were or are “insiders” (had worked or are working in education or health) emphasize that they walk a particularly fine line. They use pitbulling to promote success for their children but do not “rock the boat” to the point where they are shunned or ignored by the system. They use language to soften their advocacy and education messages. An insider to the education system explained how she used language to soften her message to the school:

So if a child has an aide they can have anywhere between six hours and fifteen hours. Asking questions like that … you know, at these meetings, to the resource teacher, “Well how did you determine how many hours my child should get? What made you give them 12 hours instead of 15 or instead of six? Can you help me understand that? (8.1., lines 262-267).

Another insider who made comments about her difficult position as an employee and parent in the school district explained treading carefully to pitbull for support:
And I explained the whole thing to them around getting caught in the cycle, right. So I said, “What can we do to facilitate it looking different so that we’re not just jumping back on the same merry-go-round? (8.1, lines 1618-1621).

When standing firm, hauling in support, or treading carefully do not result in understanding and the kinds of environmental conditions that would enable children to regulate their own behaviours caregivers have to engage in other tactics to stay intertwined to fit in, or hit rock bottom where successful outcomes for their children and themselves are undermined. Pitbulling, together with other tactics, can also lead to changes in environmental conditions that make it more likely for children to be more independent and successful and for caregivers to feel like “good” and responsible parents and enter times of respite.

5.6.3 Cultivating Connections

Caregivers use cultivating connections as another tactic to orchestrate schooling or build relationships over time with others at their children’s schools and in their communities. They build relationships to promote academic and social success for their children. Caregivers drop in at the school, make sure they encourage teachers, volunteer, and attend school-based activities and programs to cultivate connections with teachers and other school personnel. Cultivating connections increases trust from school-based personnel for caregivers and empathy and understanding for children. Caregivers who cultivate connections believe it makes teachers’ expectations more reasonable and adaptations more individualized for their children, leading to increased chances of academic success. When caregivers were cultivating connections they were more likely to overcome barriers (i.e., lack of service and support) posed by a lack of assessment or diagnoses for their children. Ultimately, cultivating
connections is about creating a safe space where children are welcomed and wanted and caregivers are respected as experts on their children. An adoptive parent described cultivating connections:

P: And I think, certainly after the first principal left, that I developed a really good relationship with the school.

R: Was that something that you worked on …

P: Absolutely. I worked on it, and I worked really hard (17.1., lines 206-211).

A foster parent explains how cultivating connections creates space where success will be more likely for her child:

I almost made sure I made friends with the teachers…They knew my name…They knew my number and they had an understanding of what [my] child had been through and what limitations they had so that they could kind of work with it, so they wouldn’t criticize…over criticize or have expectations that were ridiculously high and so they would lower the expectations a little bit…not so much around the behaviour stuff but maybe around the workload and around their listening skills, their ability to stay on-task and to concentrate (9.1, lines 39-47).

School policies influence caregivers’ attempts to build connections. Caregivers describe schools as having open or closed door policies. Welcoming and “open door” schools make cultivating connections to promote success for children easier. Caregivers feel more respect and feel they can direct less energy towards keeping up appearances as a parent.
Cultivating connections provides allies to haul in to provide support as part of pitbulling. A grandmother explains her ability to cultivate a connection with her child’s principal:

I saw the principal… like I walked [my grandson] to school every day. And I had a dog… and that dog was always allowed in the school. The kids loved that dog, and I would take him in and we’d go in the principal’s office …. you know, about once a week we would talk…. I always was in close contact with her, the principal, and I even phoned her about a month ago …. Principals don’t stay very long at a school, so she was transferred… after [my grandson] was there she was transferred and I called her and I told her what [he] was up to now…. (6.1, lines 539-561).

When caregivers are insiders to the education system (i.e., when they work or have worked in a professional capacity in the education system), building connections to promote success for their children is easier. They can use their insider knowledge to identify where to invest their time and energy to build connections. Consider the following quotation from an adoptive mother who also works within the school system:

And all schools are not created equal, it’s really important to know who is who and who the players are and what is their pedagogy, what’s their understanding of FASD, what is their understanding of mental health issues, and how are we going to work together (8.1, lines 232-236).

When caregivers are insiders they know how to position themselves and use language strategically to prevent teachers from viewing them as “problem” parents. A caregiver who
worked in the school system explained how she used language strategically to cultivate the kind of relationship with teachers that would allow her to promote success for her child:

And yah, a lot of times they do try to cut and paste [the IEP] from the year before, and then you want to respectfully talk around that. A lot of times the language they use is very ambiguous, so, “Can you help me understand what this looks like?” or “Where’s the evidence for this?” or “Is this a realistic goal, given what we know about the child?” So, yah (8.1, lines 162-168).

While having access to insider information and language associated with the education system makes it easier for participants to position themselves and use language in a strategic way, working in the system is not a pre-condition for using language strategically. Theoretical sampling indicated that outsiders were also able to employ this tactic, provided that they were connected to knowledgeable support people who gave them access to inside knowledge and language they needed to advocate effectively.

In schools with a “closed door policy,” caregivers feel unwelcome to connect with teachers and other school-based personnel, outside of typical structures that exist for parent-teacher contact. In those schools, cultivating connections to promote success for children is more difficult. A change in policy from one year to the next makes it difficult for a caregiver to build a relationship with her child’s teacher:

The whole sense of the school has changed this year. Last year we were allowed to go in to meet our students. At the classroom this year parents are not allowed in the school to drop off or pick up…. it’s school wide. And I think it’s because they
just…you know…I think it’s because the teachers didn’t necessarily want to have to talk to parents all the time….(4.1, lines 378-386).

Under “closed door” conditions, parents find it difficult to cultivate connections and feel less acknowledged and respected as experts on their children. Those conditions increase the energy they devote to tactics to keep up appearances so they can intertwine with their children and fit in as parents. Regulating the relationship with their children is also more difficult when, under closed door conditions, parents do not have the kind of information that will allow them to make thoughtful decisions (e.g., about being more involved or more distant) so they can promote children’s independence safely and both they and their children can fit in.

Caregivers’ behaviours can contribute to being shunned by the school. Data from document analysis (i.e., written correspondence between a principal and a caregiver) indicate that school personnel discourage caregivers from connecting outside the usual communication structures when the caregiver is seen as a “problem parent” rather than an ally. Being shunned by the school makes it almost impossible for caregivers to have access to the information they need to direct their energy appropriately.

Caregivers also cultivate connections with community members. Staying connected with others who have knowledge of FASD and understand the nature of FASD makes actively managing children’s schooling easier. Caregivers gain access to helpful resources and learn from others’ tactics how to promote success for their children. Participants, who live in a setting that has been portrayed over the long-term as a community of people living in poverty and experiencing marginalization, indicate they trust knowledgeable professionals
in their community. They refer to trusting relationships with workers at their children’s
daycare centres, personnel at community centres, their children’s after-school programs, and
their “friendly neighbourhood doctor.” They also trust support group members who have been involved in their lives. Easy access to trustworthy and knowledgeable long-term
connections and supports and flexible criteria for accessing support in their community
distinguished caregivers from this community. Trusted allies help caregivers by taking them
to assessment centres, attending school and assessment meetings, and helping them access
valuable resources:

One of the girls [from the drop-in centre] drove us [to the assessment] out there and
she came to pick us up. That’s what I love about all these girls up here…they help the
old when they can…you know…. I said I want the school to also know that she’s
FASD and she said, “I’ll make copies of this and bring it up there” (3.1., lines 316-319; 333-335).

In trusting relationships, caregivers feel less blamed and view the bar for presenting
themselves as “good” or responsible parents as set lower, which aids their efforts to stay
intertwined to fit in.

Cultivating connections to promote academic and social success for their children
takes much time and energy; it comes at the expense of attending to other parts of caregivers’
lives. “Open door” policies at schools and access to community connections and supports
make it easier for caregivers to build connections that allow them to move closer to the ideal
long-term outcomes of success and happiness for their children and themselves. “Closed
doors” policies in schools, which may result from caregiver action, make it more difficult for
caregivers to cultivate the kind of trusted connections that help them stay intertwined to fit in. Because caregivers feel unacknowledged and disrespected as parents under closed door conditions, they also have to direct more energy towards tactics that help them keep up appearances.

5.6.4 Anticipating Difficulties

Caregivers keep their children’s difficulties from escalating at school and their relationships with their children stable by anticipating difficulties. Anticipating difficulties that can jeopardize their children’s success in school and could make intertwining more difficult has most caregivers working hard to set a positive tone in the morning and some caregivers being pro-active by setting up back-up plans at school to prevent difficulties from arising. Anticipating difficulties is intended by caregivers to increase children’s success at school and increase the likelihood that their children would fit in.

In cycles where difficulties are anticipated to escalate, caregivers direct more energy to regulating the relationships with their children by observing behaviour closely and being proactive. A caregiver describes setting a positive tone in the morning:

I will tell him a joke on the way to school, I will tell him something so much fun we’re going to do. Like, because if he is in the van and we start talking about something negative and he’s upset, that’s going to carry through (7.1, lines 147-150).

Setting a positive tone in the morning is difficult, stressful, and particularly draining in situations where caregivers have other school-aged children to manage and their attempts are unsuccessful. Caregivers have to figure out how their children will react, choose their actions
and words carefully, be one step ahead, expect things to go off-track, and plan their next moves in advance. When they are successful their children start the day at school on a positive note and caregivers feel more positive about themselves as parents.

Anticipating difficulties that derail their children’s chances for success in school leads some caregivers to take a pro-active approach by setting up back-up plans at school. Caregivers make use of existing structures such as the Individual Education Plan (IEP) process or help set up safety plans at their children’s schools. Not only do caregivers’ pro-active efforts aim to promote success for their children but also the tactic helps them to be viewed as “good” parents. Caregivers define the IEP process as meaningful when goals for their children are focused, specific, and individualized and include both weaknesses and strengths. They find it particularly helpful when the process involves frequent consultation among themselves, teachers, and other staff. Frequent consultations support caregivers feeling acknowledged as experts on their children; being regarded as experts helps them to keep up appearances as well as stay informed to regulate relationships. Under those conditions, staying intertwined with their children to fit in is easier. A caregiver describes a cycle where she was “used as a resource” by the school:

P: I was more and more involved in sitting down with resource teachers and going ‘Okay…how are we going to make this work?’ And them working with me. I found they always worked very, very well with me as far as being willing to work as a team.

R: What does it look like when they…in your experience what does it look like when they did use you as a resource?
P: It looks like lots of telephone calls or e-mails or meetings, sitting down talking about the problems (9.1, lines 132-138).

When the IEP process is considered to be lacking in meaning caregivers will use pitbulling, being on standby, and setting a positive tone in the morning but they will not take a pro-active approach when they anticipate difficulties with the school. For them, the IEP process is not meaningful when the IEP goals are “copied and pasted” from other or older documents, too general to assist in promoting success for their children, and, especially, not involving consultation in a meaningful way. Under those circumstances, they regard the creation of the IEP as a “token process.” The IEP process becomes one more thing they “have to do,” adding to the full time nature of managing their children’s schooling. This participant does not use a pro-active approach:

I’m still fighting the fight with the principal, and I have a new key worker now who is going to come in and do this one with me. But again, it’s almost the end of the year so we are [setting goals] for next year (5.1 lines 237-243).

Taking a pro-active approach involved more engagement with the school over time, which helped caregivers cultivate connections with school personnel, which, in turn, assisted caregivers with orchestrating schooling, regulating their relationships with their children, keeping up their appearance as “good” parents, and staying intertwined with their children to fit in.

Children’s transitions (e.g., transitioning into a new grade, transitioning from a special program back into a regular program, or moving into secondary school) require
caregivers to be alert, anticipating difficulties. During an interview in the summer, a caregiver anticipated difficulties arising from her child’s transition from a special program into a regular program. She describes considering a back-up plan to promote success for her child and herself and contribute to staying intertwined to fit:

The 11-year-old will go back to the same school that she’s always been in. The only difference is instead of going to the family class and getting treats for doing her homework and behaviour, she’ll be going to regular class and there won’t be the treats and there won’t be the rewards….So that’s going to be interesting to see how long it will last and when she starts writing swear words on her homework to the teacher….I think it’s going to be very hard for her….we have the worker coming in….We are starting early now…to schedule her. And get her used to what consequences are for her actions (12.2, lines 277-285; 301-306).

During transitions, caregivers have increased concern about their children’s learning. They anticipate difficulty keeping up with peers. In particular, the looming transition from primary to secondary school intensified caregivers’ anticipation of academic difficulties. Parents with children getting ready for secondary school identify gaps in children’s academic knowledge and between children’s chronological age and their coping skills as reasons for anticipating difficulties.

There has been…some academic progress given the homework…given the work she has at home and at school…That still doesn’t mean that they’re anywhere near their ability at this time…where they should be…not even close. In fact, we’re really concerned for my daughter because …she’s going to end up going to junior high….
That will be disastrous. Absolutely disastrous. She has no foundation…academic foundation, really (11.1, lines 357-364).

To summarize, orchestrating schooling is a strategy consisting of tactics, specifically, being on stand-by, pitbulling, cultivating connections, and anticipating difficulties. Caregivers use orchestrating schooling to promote their children’s academic and social success (help them to fit in). If the strategy is successful, it can also help contribute to educators’ views of them as “good” parents. The caregivers throttle the tactics up or down depending on their children’s behaviour and the amount of support and modifications made by the school system to support their children. Simultaneously, caregivers are using other tactics to keep up appearances so they can be regarded as good and successful parents. It is difficult for them to regulate their relationships with their children by putting in a lot of time and energy to stay intertwined (together) if neither their children nor the caregivers are fitting in to the school system. Children’s behaviour, caregivers’ availability, modifications to the school environment, support from teachers, and availability of support workers are just some of the conditions that influence the amount of energy devoted to orchestrating schooling and types of tactics used. Using tactics to orchestrate schooling and caregivers’ use of tactics for keeping up appearances contribute to hitting rock bottom or reaching islands of calm, which have short-term outcomes associated with them.

5.7 Keeping Up Appearances

Keeping up appearances is a strategy that caregivers use to look like a “good” or responsible parent so they can fit in with other parents and the school system while attempting to stay intertwined with their children. To promote being viewed as a “good”
parent, caregivers’ efforts aimed at overcoming their children’s challenges allow them to fit in as parents. Caregivers indicate that presenting themselves as “good” or responsible parents is an ongoing challenge. Their children’s disorders are invisible, their behavioural difficulties are unpredictable, and their unexpected strengths and weaknesses make it hard for others to set realistic expectations. Caregivers are often blamed for their children’s behaviours, regardless of whether their status includes being a biological parent who “caused” children’s brain damage. An adoptive parent said the following:

I think that not being judged is huge with FASD…not only as a parent and whether you did [the drinking] or not…whether you exposed them to the alcohol, but the behaviours that happen and the bizarre things that can come up…(4.1, lines 762-767).

Participants try to keep up appearances by employing the tactics of sharing information, reframing, and redefining self, while they simultaneously orchestrate their children’s schooling and regulate their relationships with their children. Figure 5.3 provides a visual image of the strategy, keeping up appearances, with its tactics.
Figure 5.3 Keeping up Appearances

One participant, a negative case, explains about not being concerned about keeping up appearances. Because of her history in her community, presenting herself as a “good” and responsible parent was not within her reach. Rather than putting her energy into an image
that was not credible, she opted out of keeping up appearances and focused on sustaining her relationship with her child at that particular point in time:

I’ll call somebody and say “I have lost my freakin lid…you had better get over here. I’m not dealing with them anymore.” I’ll call the social worker. I’ll say “that’s it…I’m spanking the kids. You can send whoever you want later today but they’re getting a spankimg right now” and I hang up the phone.

R: And then what happens?

P: She calls back: “Why are you spanking them for? What kind of help do you do? What do you need? What resources are going to help you with this?” And I’ll say, “Well…get them into swimming class. The boys are climbing up my walls…I can’t handle it. He needs a Jungle Gym.”

R: Does it happen?

P: Yes…she got me a preservation worker who’s getting me the information that I don’t have time to go look for.

R: What’s a preservation worker?

P: To preserve your family…. Just as it sounds…they preserve your family. They keep your family together (12.2, lines 690-714).
Using tactics to keep up appearances so caregivers can stay intertwined and fit in as parents is hard work, which takes a toll on their physical and mental well-being. The work is especially hard when caregivers receive constant negative feedback for their efforts.

It is more difficult to share information, reframe self, and redefine self under conditions of poverty and stigma. Caregivers living in poverty are more likely to be blamed than caregivers with more financial resources when their children don’t fit in. Parents find it more difficult when resources are limited to promote themselves as “good” parents. Caregivers who lack financial resources have more difficulty paying private health professionals; those professionals might be more likely than public teams to give a less stigmatized diagnosis, such as ADHD, or obtain individualized support for their children. Being unemployed and living in poverty creates challenges for caregivers to attend meetings at their children’s schools. An unemployed mother who travels across town by bus to attend courses to upgrade her employment skills describes being unable to attend after school meetings with her child’s teacher: “The teacher was telling me just get yourself to come by and see me and talk about the kids’ progress. It’s not happening” (2.1, lines 489-490).

5.7.1 Sharing Information

All caregivers use deliberate sharing of information as a tactic to keep up appearances. In some cycles of intertwining to fit in, keeping up appearances or being perceived as “good” parents is contingent on sharing minimal information or even withholding information from the school. Some biological parents decide to withhold some information, such as the birth history, by only releasing part of an outside assessment report to the school or withholding the assessment report. They regard their control of information
as reducing the shame and stigma attached to FASD or assisting them to keep up appearances. Under those conditions, they are more likely to be viewed as parents who are good and responsible.

To promote being seen as a “good” parent, caregivers carefully control the amount of information they share with school personnel and outside professionals. They control the information they share about their children’s birth histories, results of outside assessments, and their own and their children’s difficulties so they can obtain help for their children and promote their appearance as “good” parents. When caregivers provide explanations for their children’s behaviours, they are less likely to be blamed as “bad” parents. A foster parent said the following:

I do it for myself…I do tend to play on the sympathies of the teachers and I do share a little bit of the kids’ life story…I try to stay within parameters of keeping the kids’ privacy but at the same time I want them to realize how damaged these children are and have some sort of…you know…compassion for them so that they’re not just another kid…. (9.1, lines 398-404).

Because I interviewed participants over time, I observed some participants choosing to share information and others choosing to withhold it. Caregivers do not always control information using the same approach; they vary the amount of information they share over time to make sure they keep up appearances and stay intertwined with their children to fit in.

Sharing information with the school generally helps caregivers promote their image as “good” parents and was used most frequently by caregivers. Caregivers want to avoid being blamed by teachers and others in the educational environment when their children
struggle or have problems with their behaviour. Because children with FASD “talk the talk, but don’t walk the walk,” meaning their verbal abilities often mask their poor comprehension, teachers who do not have specific knowledge of FASD find it hard to understand why children behave inconsistently.

Sharing information is particularly challenging for biological parents, who struggle with decisions to release personal information about children’s alcohol exposure to the school, because such information is inconsistent with their own and others’ definitions of “good” and responsible parents.

Purposefully sharing information with professionals outside the school helps caregivers manage others’ views of them. Three caregivers who were involved with social services at the time of the interviews indicated that carefully sharing information about their own well-being and what is going on in family life with social workers resulted in them being regarded as “trustworthy.” Relationships with social workers characterized by trust are more likely to lead to supports being available to facilitate children’s success and to help caregivers stay intertwined with children.

It is more difficult to purposefully manage sharing information when participants who identify themselves as aboriginal perceive a “double stigma” as members of the Aboriginal community and biological parents of children with FASD. Having labels attached to children, by virtue of their ethnicity, complicates managing the flow of information to schools. When deciding whether to share information caregivers have to carefully consider potential further stigmatization for their children while reducing the likelihood of being viewed as irresponsible parents because they withhold information from school personnel.
P: It used to be said that if you were Native, you’ll be diagnosed with FASD. If you are white, you will be diagnosed with ADHD.

R: I’ve heard that.

P: For God forbid if a white woman drank. Only Natives are drunks!

R: So there’s that stigma…that patronizing…

P: Yeah! So if you get adults with ADHD, it’s a good possibility that they’re really FASD, especially if they’re white. And it’s a good possibility that a lot of the children that have been diagnosed with FASD…it’s a good possibility that their parents really didn’t drank.

R: It’s ADHD.

P: But way back in the day and you were a Native, your child was FASD…plain and simple. And if they didn’t have any facial features, then they said you were a bad parent. This is because you taught your children wrong.

R: So either way, you can’t win (12.1, lines 377-392).

Being connected to support is a condition that helps biological caregivers overcome stigma and purposefully share information with the school so they can keep up appearances and stay intertwined to fit in. When caregivers are connected to people who they trust, affirm them as parents, and help with the flow of information, keeping up appearances is easier.
Well, the key worker has been helpful. I find her helpful as a resource for ideas but also just as somebody to talk to and bounce things off of and hear how I’m doing…you know (9.1, lines 251-255).

Caregivers connected to supports were more likely to be open about their children’s diagnostic status. Support groups encouraged the caregivers to share information with schools and praised them when they shared potentially beneficial information. When caregivers were praised for their actions to support their children their positive feelings about themselves as parents increased and they felt they were keeping up appearances.

Caregivers also share information with respite care providers to make it possible for them to take time-out to replenish their energy. When respite care providers lack knowledge and understanding of FASD caregivers may have to initially increase the time they spend educating them about FASD, so they can take time out. They have to invest energy now to be able to replenish their energy later:

I have more of a luxury in that I do have some funding available to have support workers so that I could…I can take a break, or I can work, or you know, it’s my choice to do that. But then the dilemma around that is…or that I’ve found is that finding people that have the skill set or the ability to acquire it through me training them in terms of how to manage what might come up with this child and how to navigate through the time that you spend with her, because it’s not typical. I can’t bring in the girl next door to babysit, so to speak….. (16.1, lines 177-185).
Caregivers also view sharing information about assessments with the school as increasing their children’s risk of being stigmatized, which in turn will undermine their attempts to orchestrate schooling to promote social and academic success for their children. Caregivers, who perceive special education criteria as ambiguous and who view identification of their child as a child with special needs as unhelpful, are more likely to withhold information. Also, under conditions where their willingness to share information during previous cycles or with older children did not result in support for their children, caregivers were more likely to withhold information from the school. For example, a biological parent who had several of her children assessed decided not to have her youngest child assessed prior to entering kindergarten because she wanted to see if he could “get by” without engaging in the intrusive diagnostic process.

5.7.2 Reframing

When participants are faced with their children not fitting in, positioning themselves as “good” or responsible parents is more difficult. For biological parents especially, positive feelings about their parenting decrease and their grief, layered with guilt associated with the affected child, increases. Caregivers use reframing as a strategy to keep up appearances, given the nature of cycles of intertwining to fit in. Reframing involves caregivers changing the meaning they attach to the behaviours of others, including their children. In general, caregivers reframe relationships with professionals and their children’s behaviour. Biological parents reframe children’s assessment processes.

When caregivers judge their children to be falling behind academically and doing poorly in social interactions some choose to disengage from the school and potentially
helpful supports to protect their efforts to keep up appearances. Other caregivers reframe their relationships by moving from viewing teachers as barriers to success for themselves and their children to viewing them as potential allies. Reframing teachers as allies makes it easier for parents to stay engaged with the school, attend meetings and have conversations about their children. A caregiver who previously disengaged from the school describes reframing her relationship with her child’s teacher:

Anyway, the last talk we had…it just seemed to be enough. It just felt really good. Suddenly…you know… I’m wanting to accommodate her…she’s accommodating me…she’s going to phone me if she feels that there’s something wrong (11.1, lines 314-318).

Caregivers also reframe relationships with others in power positions (e.g., social workers or principals) so they don’t jeopardize their efforts to fit in and fit their children in. Moving from viewing a social worker or key worker as “invading their privacy” to being helpful and supportive helps caregivers stay engaged so they can employ their other tactics to intertwine to fit in. It also prevents caregivers from being regarded as uncooperative. A participant reframed her relationship with her social worker so she could act more like a responsible parent.

You know when I started coming to the FASD groups and started realizing you know …my son needs a lot of help, I can’t keep being rude to the social workers…I can’t keep pushing people away…. (12.2, lines 517-521).
Belonging to a support group creates conditions that facilitate keeping up appearances through reframing. Support groups provide caregivers with opportunities to reflect on themselves and their relationships with others; caregivers learn from others about how to project a positive parenting image.

So I had said to [the group members] “Well you know, instead of saying a label, say, “my child is doing this and that and that, and I really need help. I don’t know what to do anymore.’ And sound desperate.” Because it’s Family Services, that’s probably going to help (7.1, lines 390-393).

Almost all of the biological parents reframed the assessment process to minimize potential threats to their image as “good and responsible” parents by themselves and others. Data from interviews and document analysis and my experience in schools sensitized me to differences in implementation of policies from school to school, even when children qualify for extra assistance for their chronic health conditions. The data also sensitized me to imprecise criteria for deciding when children receive supports. The diagnostic process for children presented all biological parents with challenges in promoting their image as “good” and responsible parents. Reframing the diagnostic process from an invasive process that undermined keeping up appearances as a “good” parent to a positive and helpful process increased the likelihood that caregivers would pursue a diagnosis for their children. They temporarily sacrificed their image as “good” and responsible parents for the longer-term good of their children, which in the end would reflect positively on caregivers. Engaging with the diagnostic process garnered affirmation from physicians, key workers, and others in
their communities for acting like a responsible parent. Parents can begin by framing the process negatively.

So we go there at 8:30 and the child goes separate from you and I was like…it was emotional because he asked “How long did you drink? What did you do?” Personal, opinionated questions they asked me …. (1.1, lines 620-626).

A biological mother then describes reframing the process positively.

I need support for my daughter…she’s going to learn…she’s going to have a heck of a time, I’m thinking to myself, but not look at [the process] as a negative thing but as a positive thing, so that I can learn as well and learn with her…yeah…so that’s how it worked out to be (1.1, lines 482-486).

Being confronted with the permanent nature of their children’s brain damage due to exposure to alcohol and considering their potential contribution motivates caregivers to reframe their children’s behaviour. They might emphasize genetic or environmental contributions to their children’s conditions and deemphasize the contributions of prenatal exposure to alcohol:

He is Attention Deficit Disorder, which some of it comes from being FASD, but on his report it says severely because he also comes by the ADHD naturally. So even if I hadn’t drank, my son would still have problems…. (12.2, lines 147-150).

Reframing their children’s behaviours and emphasizing factors other than prenatal exposure to alcohol (e.g., other medical conditions or the influence of siblings) helps caregivers exercise agency and employ tactics they need to keep up appearances, continue orchestrating
their children’s schooling, and stay intertwined with their children to fit in. For biological caregivers, reframing children’s behaviours minimizes guilt.

### 5.7.3 Redefining Self

A third tactic caregivers use to keep up appearances so they can stay intertwined to fit in is redefining themselves. Redefining themselves involves reflecting on themselves and changing their identities. A biological mother captures the consistent effort that goes into redefining self to promote an image of a “good” parent and avoid “hitting rock bottom:”

> And I only do it [the hard work] because if I fall off the track, then I get like emotional and miserable. If I walked around with a smile on my face all day, it’d hurt. I mean…all day! Pretending to be somebody I’m not….I have to do what is going to make my parenting easier on myself because if I’m…like I said, if I walked around like this I wouldn’t be able to cope…I wouldn’t. I’d be miserable, I’d be upset, I can’t do this…I give up … (1.1, lines 1054-1057; 1115-1120).

Under conditions where children’s behavioural difficulties escalate to the point where children have to leave the school or children experience frequent medical illnesses associated with FASD, children might stay out of school for significant amounts of time. Having children out of school interferes with caregivers’ presentation of themselves as being “like” other parents. They have to direct most of their energy and time towards regulating their relationships with their children to stay intertwined to fit in.

Caregivers spend significant amounts of time teaching their children when they are not in school. The injection of time and energy to regulating their relationships with their
children to try to change their children’s behaviour can contribute to distancing themselves from others, exacerbated by others’ lack of understanding of FASD. Being distant and different from others can result in caregivers reflecting on themselves and redefining their identities from someone who is “so alone” to “someone who “likes to be alone,” is “not the group type,” or is the “do-it yourself kind of person.” Redefining themselves helps prevent caregivers from hitting rock bottom and moving from being disengaged to being cut off from others.

When children spend considerable amounts of time outside of school caregivers might redefine themselves as “teachers,” an identity that goes above and beyond the identity of teacher taken on by most parents of typical children. Some caregivers redefine themselves as their children’s teachers during prolonged periods of time with their children at home; they spend hours teaching their children academic and life skills at home and take pride when they see their efforts paying off:

Like with all the work I do with her and them, they have to do things neatly. I don’t accept all this scribbling and stuff. … Anyway…when this stuff happened in February and I said I was going to keep her home from school, she was home for two or three days and I started her in writing. She’s becoming a beautiful writer because I’ve given her my time to teach her and her teacher, ‘Oh! You’ve got such beautiful writing.’ She never started her learning that and she didn’t give her the chance….

(11.1, lines 510-524).

Redefining themselves as their children’s teachers helps caregivers promote their image as “good” and responsible parents.
When caregivers redefine themselves as teachers the time consuming nature of managing their children’s schooling and regulating their relationships with their children, all at the expense of attending to other aspects of self, is more acceptable. Reframing supports some of the other tactics caregivers use to stay intertwined with their children. They also feel they are making progress towards the ideal outcomes for which they are striving.

Biological mothers frequently redefine themselves as people who “made mistakes in the past” and “having come a long way.” Caregivers redefine themselves by putting “irresponsible” behaviour behind them. A mother redefines herself by saying: “I was drug addict and I will never let anything control my life or take over it” (12.1, lines 656-657).

Redefining self in a positive way is facilitated by available support which provides caregivers with opportunities to reflect on themselves. In the presence of others who understand the nature of FASD and refrain from attaching blame, caregivers can redefine themselves as “good” more easily and feel that image is reflected back to them. Support groups are a place where caregivers connect with other parents of children with FASD. The groups support them to let down their guards temporarily. A caregiver who regularly attends a support group in her community describes the support group as finding a place where she can fit in as a parent: “We socialize with parents that has the same issue and we share it and we have that delicate moment that we share amongst us” (2.1, lines 354-356). A biological caregiver also linked regular attendance at a support group with redefining herself as “responsible” and “confident:”
It gives me the comfort, just being there [at the group] and I feel confident, dealing with everyday life with me and my family. It makes me more confident. Yeah…I’m doing the right thing for my kids actually (2.1 531-534).

Support group longevity, with high levels of trust amongst group members and skilled and knowledgeable facilitators, is valued by caregivers. Support groups that are easily accessible (i.e., in close proximity to where the caregiver lives) and with childcare provided for the child or younger siblings make it possible for caregivers with limited resources to have space to reflect on themselves and redefine themselves in positive ways. In the presence of other caregivers who understand FASD and under conditions of growing trust, caregivers have opportunities to change their identities in ways that assist them in intertwining to fit in. One caregiver (a negative case) indicated being connected to a support group was unhelpful, in part, because it added to the stress of keeping up appearances. She felt set apart from other caregivers when she could not attend the group regularly because the group was not close by and offered no child care. The mother could not rely on extended family to provide childcare because the extended family members lacked knowledge and understanding of FASD. Having group attendance available but blocked by barriers prevented her from redefining herself as a “good” parent.

Support around redefining oneself as a “good” parent can arise from connections to a go-to-person. A go-to-person is someone who “has their back,” is “in their camp,” and is “listening,” “believing,” “getting it” and “knowing the history.” Go-to-people “keep you going” and “are there when you need help” because they are someone the caregiver has learned to trust over time. Several participants indicated that their go-to- person often stayed
in their lives and affirmed them as “good” parents. Being affirmed makes redefining yourself easier. Some participants identified the go-to- person as the principal or vice-principal at their children’s schools. An adoptive mother, who had been labeled negatively by school personnel, describes being affirmed as a good parent by her go-to-person which helps her redefine herself:

She knew me and I gained a relationship prior to going into the school system with her and when I told her that …the principal had dismissed me as an emotional parent….I said, ‘You know, you know me,’ and I said, ‘Yes, I was emotional and I was in tears but my son was being bullied and was being targeted and I don’t know why when I’m tearful about that… And she said, “Well…you’re not an emotional parent…. I know who you are….”’ (4.1 lines 434-440).

Conditions where caregivers receive consistent negative messages from schools, especially when not connected to regular supports where they are affirmed as “good” parents, create difficulty for parents to redefine themselves positively. Those parents may disengage from the school:

And every day that I pick him up… he has a communication book so that they can let me know how his day went. And it gets really frustrating because it’s not just… it’s every single little thing that he’s done is in there, and it gets… the stress is just like… to myself is like…. So now I’ve taken a step back (7.1, 120-124).

Receiving negative feedback as a parent, in spite of throttling up other tactics for keeping up appearances, can move caregivers into rock bottom where they temporarily give up on trying
to present themselves as “good” parents and orchestrating their children’s schooling.

Conversely, when caregivers can redefine themselves positively they are able to push back against negative reactions to them as parents where they feel little control. Because they feel that they fit in with other parents when tactics are successful they are also more likely to use strategies to orchestrate their children’s schooling and stay intertwined with their children.

To summarize, the strategy, keeping up appearances, consists of the tactics, sharing information, reframing, and redefining self, through which caregivers try to promote themselves as “good” and responsible parents (to fit in as parents). Depending on their success, they throttle their tactics up or down to keep up appearances. If they are throttling up their tactics they have less time and energy available to regulate their relationships with their children so they can stay intertwined (together) to fit in. Stigma, living in poverty and access to support are just some of the conditions that influence the energy and time caregivers devote to promote success for themselves as parents (keeping up appearances).

5.8 The Critical Junctures: Hitting Rock Bottom and Reaching Islands of Calm

Depending on the success of using strategies to intertwine to fit in, caregivers cycle either into rock bottom or islands of calm. Hitting rock bottom represents a critical juncture where, after unsuccessfully using tactics to orchestrate their children’s schooling and keep up appearances, caregivers temporarily give up on using those strategies. Reaching islands of calm represents a critical juncture where, mainly as a result of using tactics successfully and maintaining their strategies, caregivers move into times of respite when intertwining to fit in is easier and caregivers can attend to other aspects of self. They can attend to other aspects of self because their children are functioning more independently and are achieving some
academic and social success and caregivers have space to examine their needs. Both junctures represent times where caregivers take stock of the effects the actions taken to reach their long-term outcomes for their children and for themselves.

Being intertwined, with the energy and time devoted to regulating relationships, changes depending on whether caregivers are hitting rock bottom or reaching islands of calm. During cycles where caregivers hit rock bottom, regulating relationships with their children needs more time and energy because there is too much or too little distance between caregivers and their children. Too much or too little distance occurs as caregivers try to regulate relationships with their children.

At points in cycles where caregivers reach islands of calm, intertwining to fit in is easier and caregivers and their children are more comfortably intertwined; regulating relationships seems to have placed them in a position where there is not too much or too little distance so they need to devote less time and energy to regulation. The time participants spend at rock bottom or islands of calm depends on the conditions they encounter.

Hitting rock bottom and reaching islands of calm are associated with short-term outcomes. Short-term outcomes associated with critical junctures allow caregivers to figure out where they are in terms of using their strategies and cycling back in. Experiencing despair, anger, exhaustion, disconnection, and feeling drained, shunned, and side-stepped by the school system are just some of the short-term outcomes associated with hitting rock bottom. Short-term outcomes associated with islands of calm include time and space for personal development, tranquility, hopeful signs, and receiving support (from people or programs).
5.8.1 Hitting Rock Bottom

Hitting rock bottom is a critical juncture where caregivers temporarily move out of actively managing their children’s schooling and keeping up appearances. They have to take time out to regulate their relationships with their children outside the system and figure out how to cycle back in to their strategies. A specific incident can serve as a tipping point to hitting rock bottom. An adoptive mother describes her tipping point:

The difference between my son and the in-group just got stronger and stronger and more set. He had an opportunity to go and play and jump on the trampoline of one of the children of the in-group, who lives just next door. And I noticed that he wasn’t allowed on the trampoline. And then when the movie started… almost all of the students from his class were there without their parents, and they would not let him sit with them (crying): And that’s after three years of putting it [the goal of social integration] on the IEP, to make any kind of integration meaningful. And so it was a watershed moment (17.1, lines 331-362).

Participants have vivid descriptions of hitting rock bottom. One participant realized how my visual model of hitting rock bottom captured her despair:

Everything that I was trying to do that I believed would make a difference for this child kept getting twisted. ..At that point,…that’s the point that I would have gone, “That’s it, I’m out of here. I don’t… you know, I’m done.” Like, I hit this point [rock bottom], really, at that point [the meeting] last Spring. Where I just thought, “I don’t need this” (16.1, lines 1036-1040).
Caregivers’ realizations that their strategies are not promoting academic and social success for their children or helping them to be seen as “good” and responsible parents leads to them suspending orchestrating schooling and keeping up appearances.

There is a sense of despair, anger, disconnection, and exhaustion, when caregivers need to regulate their children’s behaviour 24/7 because their children can no longer attend school. Constant caregiving puts the relationship between caregivers and their children in jeopardy, as well as other goals for caregivers such as looking for employment and spending time with other people. In the following quotation, a foster mother describes the sense of exhaustion she experienced when, over time, her strategies are unsuccessful.

We’ve got to take care of these kids, and all the challenges that manifest out of that, and then we’ve got this whole other package of fighting tooth and nail for services …So you’ve got these two energy drainers… and there’s just that point at which we all go, “God, I’m done. I can’t do this. I can’t do this another day. I can’t do this…” I’ve been there, “I can’t do this another minute.” Like, so completely drained. Like emotionally and physically, it affects everything (16.1, lines 1257-1261).

When caregivers’ strategies to stay intertwined to fit in are not working and they hit rock bottom they disengage from the schools. There are cycles where caregivers don’t see it as possible for their children to be at school and there are cycles where caregivers are requested to keep their children home. Almost all participants described a general distancing from people they encounter because of a lack of understanding of FASD and the full time nature of actively managing but at rock bottom participants move from distancing themselves from others to disconnecting entirely. They describe “getting to the end of what you feel you can
manage,” “being done,” “being in pieces,” and “being at the end of your rope.” When at rock bottom, all caregivers express a loss in faith in the educational system. The following quotation describes the kind of disenchantment caregivers express when at rock bottom:

I actually honestly think that these kids would be better off in a special school…not a special classroom because sticking kids in a special classroom and now they’re labeled by all the other kids and now they’re still getting picked on because they’re in the ‘special’ classroom. It’s kind of ironic because I think they’ve done the same thing with kids that are disabled and that kind of works…it teaches kids empathy and compassion and stuff but when you’ve got an invisible disability, I don’t think it’s teaching other kids things unless you can really get in there (9.1, lines 147-159).

When caregivers perceive schools to persistently respond negatively or shun parents, caregivers are more likely to disengage. Because caregivers perceive their children as “unreliable historians” due to the children’s difficulties with language and memory, they rely on information from the school to regulate their relationships with their children. When they are shunned by the school, they do not know if their tactics are working, how to regulate relationships, and how to direct their energy to stay intertwined to fit in. A foster mother described the conditions that lead to hitting rock bottom where her positive feelings about herself were diminished.

They were going so far as to be overriding me, like refusing actually to communicate with me and communicating directly with the social worker, because she’s the guardian. And so I was left out of the loop of communication (16.1, lines 1090-1093).
When tactics used to keep up appearances are unsuccessful caregivers feel that they are not accepted as parents and are blamed for what is happening to their children. They see themselves as different from other parents and as not appearing “responsible and good.” When biological parents are not able to prevent their children from failing academically and in social interactions and themselves from being regarded as bad parents, their grief, layered with guilt associated with the affected child surface:

   But for me it’s not just the grief, it’s the guilt too. It’s just sooo...it just...like I go so far, you know [to overcome it] it’s like I’m on my way to Italy and I get as far as Paris and then I end up back in Canada again. Like why can’t I go...right...but that’s FAS...right (5.2, lines 168-171).

At rock bottom, caregivers go into a holding pattern where they are focusing on maintaining caregiving and regulating the relationships with their children. Caregivers wait it out when they hit rock bottom by not interacting with the school system. They refer to “not bothering,” “just going through the motions,” “just leaving it,” just “getting through the year,” and “not pushing it.” For some cycles, hitting rock bottom has a short duration; for other cycles, hitting rock bottom lasts for a long time.

Insufficient support for children in schools, unpredictable school environments, lack of knowledgeable school personnel about FASD, and ambiguous or inconsistent special education criteria for support increase the likelihood caregivers will hit rock bottom. Those conditions also increase the likelihood that hitting rock bottom will last longer. It becomes less likely that caregivers will hit rock bottom or stay at rock bottom when they have access
to formal (e.g. respite care, childcare workers, support groups or key-workers) or informal supports (e.g. extended family).

School environments are unpredictable given high staff turn-over or changes in rules and regulations, such as union rules pertaining to the substitution of support people. Caregiver actions (e.g., staff burn out because caregivers rely too heavily on staff to regulate the children’s behaviour) can contribute to unpredictable school environments if the staff change to protect themselves. A caregiver describes unpredictable school conditions that resulted in her son’s resistance to attend school and hitting rock bottom:

At the beginning of the school year his teaching assistant was off frequently and I was really frustrated so I had gone in and said, “You know,[my son] can’t have the instability because the way the substitutes work is that they have to go through a list of seniority and they have to do it each day, so if the most senior person is already working, they go the next person so they never know who’s going to get called in to substitute and so he had, within the first 15 days of school this year, he had his SEA for three days and he had 12 other people. He does not work well with people he doesn’t know…takes him a long time to build a relationship, so he was just…like nothing was happening for him and he was really frustrated and confused and didn’t know what to expect when he went to school. [He] started resisting going to school (4.1, lines 8-19).

Using tactics to orchestrate schooling does not prevent parents from being faced with changes in the supports their children receive, which undermines all of their efforts to have their children succeed academically and socially. When children are not supported despite
caregivers’ attempts to orchestrate for success, through pitbulling, cultivating connections, being on stand-by, and anticipating difficulties, their children are less likely to fit in and tactics to keep up appearances do not prevent parents from being regarded as “bad” or irresponsible parents. Feeling like their efforts are undermined and unrecognized increases the likelihood that parents will give up for the short term and hit rock bottom.

Power differences make it more likely that caregivers will hit rock bottom. Foster parents, such as the foster parent quoted below, view themselves as experts on their children but their relative lack of power, which is expressed in interactions with others (e.g., social workers) who have power to make decisions, leads to them feeling unacknowledged as parents. They are not regarded as having a long-term investment in the children and do not hold legal decision-making power.

And so if you push the envelope to the child’s social worker to get whatever it is, a service, a recommendation, a referral, a this, or a that, then you can get that reactive piece of, “No, I’m not doing that. I don’t see that as necessary.” You know, like they make the judgment call. And I think that’s the frustration that a foster parent has…. I don’t have that freedom. I think in the end, that would probably be the one factor that would push everything to end, really, would be just that… and I’ve seen that in some foster parents because we’re foster parents. Where eventually… like you can just only can do it for so long, you have so much energy and then there’s this cut-off point where you just go, “Whatever” (16.1, line 1651-1657).

When caregivers can rely on easily accessible and knowledgeable support they can reduce efforts to orchestrate schooling and keep up appearances and replenish their energy to avoid
hitting rock bottom. Caregivers who were able to anticipate or predict their need for support were less likely to hit rock bottom or stay at rock bottom for long periods. A caregiver who can predict the need for support and has family available can take time off and undertake self-care essential to sustaining her relationship with her child.

Yeah…and it [managing] takes a lot of my energy but I’m really looking forward towards this week because I get a day off. My oldest daughter is going to watch them so I go out to the movies…. Like I need to do self-care (1.1, lines 188-191).

Lack of support from extended family and lack of resources to purchase support (e.g. childcare) decrease the likelihood that caregivers can take time off. Many caregivers do not seek support from people with the lack of knowledge about FASD which reduces the respite they need to replenish the energy they require to regulate their relationships and stay intertwined to fit in:

We’ve gone through the process of interviewing people that do respite in their home, and nobody is willing to take on this child with her package of issues. Because there’s, you know, safety issues, and people are not comfortable with it. You know, and I respect that. I mean, it’s a really big package. If you’re not living it on a day-by-day basis, you don’t really get it (16.1, lines 234-239).

Caregivers, who live in a setting that had been consistently portrayed as a community of people living in poverty and experiencing marginalization, indicate their connection to their community decreases the likelihood they would hit rock bottom or stay there for a long time. Five of six participants living in this community felt connected to their close-knit
community, which resulted in feeling supported and accepted. Participants refer to everyone knowing one another, having long term connections with each other, and trusting members of the community. Caregivers feel able to connect their children with support and connect with other parents and professionals who understand FASD. They describe access to counselors, key workers, childcare workers, support groups and community centres where drop-in visits are encouraged for caregivers and their children.

These caregivers find support and services are available for themselves and their children in close proximity without “proving” they need support. Being accepted and embraced by their community reduces the energy and time they need for tactics to keep up appearances. Connections to helpful and knowledgeable support people also assist them in orchestrating their children’s schooling, leaving time and energy to focus on regulating their relationships with their children. When they hit rock bottom, the duration is shorter. A caregiver who lives in a close-knit community describes the availability of support and services in her community.

Not only that but after school there’s a program where…like I said to her building blocks …a person comes in once a week…. If I need him to be there at her school, he will be there….and not only that but people that I work with that have known my family and known where I’ve been in my life … and support…cause I need the support myself, too, …they check in with me (1.1, lines 535-539).

One participant, living in a setting that had been portrayed over the long-term as a community of people living in poverty and experiencing marginalization, presented a negative case. She felt disconnected from and unsupported by her community and did not
access available supports. When her child’s school placement was jeopardized as a result of an escalation of his secondary disabilities, keeping up appearances was difficult for her. She hit rock bottom but planned to move away from her community where she did not feel affirmed and accepted as a good parent.

5.8.2 Reaching Islands of Calm

Reaching islands of calm is a critical juncture where caregivers move into times of respite where intertwining to fit in is temporarily easier. Persistent actions from caregivers in supportive conditions increase their abilities to fit their children and themselves in and “buy” times of respite when their children are happy in school, stay in school, and keep to their routines. In these circumstances, caregivers feel positively about themselves as parents and are regarded by others as “good” and responsible parents. Their children provide the evidence to support that claim. Biological caregivers describe islands of calm as times when feelings of guilt associated with their alcohol use are less prominent.

The reduction in time and energy devoted to orchestrating schooling and keeping up appearances at their children’s schools allows caregivers to attend to other parts of their lives, specifically, hobbies, work, social groups, or volunteering for special events. Experiencing some tranquility and having space for self-care decreases the energy and time to regulate their relationships with their children so they can stay intertwined to fit in. The following quotation captures the islands of calm caregivers are trying to achieve.

So I just mean success in terms of that she was able to stay in school, to have some successful days where there wasn’t high levels of frustration or anxiety that lead to, you know, behaviours in the end. And that she actually liked going to school. To me,
that’s the better measuring stick than anything, is the fact that she would get up in the morning and be happy and want to go to school (16.1, lines 381-390).

Islands of calm can last for a brief (e.g., a few days) or longer time (e.g., a school year); however, like hitting rock bottom, islands of calm are cyclical and their effects are often short-term:

I was getting called in. My boss was always like cranky so I was like “I’m sorry…this is my kid, I have to go…I’ve got to do this.” And income assistance was pretty nice because he let me go back on because I was trying to keep my stuff together because I went back to school. I couldn’t do the GED tests…I have bad anxiety myself so every time I got in that room, my mind would go blank. So…I said, “I’m going to go get a job,” and then I was working…I was happy…everything was paid…the rent and everything. It was like “Yeah”…I felt really good about myself and then with him…always getting called in… “Hey…you’ve got to come and get him…something happened,” I just couldn’t work and now I’m starting to think I want to go back to work again but is it like going to be the same thing? (13.1, lines 184-192).

The inherent nature of their children’s conditions, as well as the instability of the school system, for example, changing teachers, principals, and key workers, makes it difficult to reach islands of calm that can last for the long-term:

P: And then in Grade Two, where she was still in the same program…

R: Same social development program.
P: Same social development program, but now a complete shift. Everybody was new. New teacher, new assistants, completely different. The kids were the same. And a different style. A really different style of teaching, where this new teacher believed in full integration for all special needs kids. So she went from what I would say is a more protected setting to less protected. In that now she was integrated into a regular classroom….so that’s when she started to really, like what I would consider like fail (16.1, lines 391-402; 447-448).

When children’s behaviours become more mature or they make scholastic progress caregivers have a sense that their children are moving forward. They feel they can throttle down their tactics to promote success for their children and for themselves as parents because they see positive signs. A caregiver’s perception of her child progressing towards regulating his own behaviour contributes to her temporary respite, in part, because she can decrease her energy and time regulating their relationship:

P: We have a better outlook right now that school’s going to go better than we did the last time we talked.

R: Okay. So tell me about that. Why did it change?

P: Because his little mind just…his synapses just went off because he’s starting to repeat stuff to us…. He’s more aware of how his behaviour is (12.2, lines 215-219; 246).

Caregivers’ knowledge of FASD contributes to them reaching islands of calm through their ability to obtain assessments for their children. Without assessments, caregivers lacked the
specific knowledge to leverage the tactics in orchestrating schooling to stay intertwined to fit in. Lack of assessment makes it more difficult for caregivers and schools to do their part and implement necessary supports. Parents who can assist their children to access necessary supports are more likely to be regarded as “good and responsible” parents. As one parent said, “without the assessment, teachers keep running into a brick wall.” Another caregiver said, “As long as she’s not assessed, [the school] can only go, “well…maybe it’s because she missed so much school…maybe it’s just because there’s problems at home…” (12.2, lines 80-86).

School environments that increase the likelihood that children and caregivers will reach islands of calm include children being: assigned a knowledgeable teacher and/or assistant or aide; included in a smaller group with additional academic support; provided with appropriate and targeted interventions; and included in classrooms where the environment is adapted to make it less likely that children will fail. While caregivers actively use tactics to put supports in place through orchestrating schooling, they cannot be successful without the potential for schools to respond to their actions. The following two quotations capture favourable conditions.

He had an amazing teacher, just an absolutely amazing teacher. And that made all the difference in the world to his wanting to go to school, to his enjoyment of school, to his feeling part…and she made sure…that everyone was included (17.1, lines 131-13).

R: What does a good teacher for a child with FASD look like…in your view?
P: Somebody that’s willing to look at things differently because he’s not going to learn. Somebody that’s willing to adapt their teaching to his needs… Rather than expect him to fit into their method of teaching…she was willing to try a different way; she was willing to work with the SEA and figure out another way to get to the same goal (4.1, lines 406-414).

Some caregivers commented on the importance of principals in creating conditions in schools that could support islands of calm. Principals who understand the nature of FASD are flexible in the way they implement supports in school, work around systemic barriers to support children, and increase the likelihood caregivers and children can reach islands of calm. They have positive effects on activities in classrooms.

If you have a good administrator who understands what’s going on and can work well with the staff, then you’ve got a good flow. If you have a poor principal, as we have now, it all goes to hell. And we’ve noticed that…you know…because there has been many changes happening with the principals (11.1, lines 39-43).

Caregivers also refer to policies that affect their abilities to reach islands of calm. They indicate that children who have been assessed and identified as children with FASD are inconsistently designated under Ministry of Education criteria in special education categories that are attached to additional funding and extra support. Some parents indicate their children can be classified as having a behavioural difficulty which is not eligible for additional one-to-one support:
She’s in a specialized program, but it is social development, it was not specialized for FASD or anything, it’s just simply a social development class that’s behavioural based…. So that’s all she qualified for in the end. So in moving from Kindergarten to Grade One, where they did some kind of assessment to determine, … I mean, I guess to get a designation…. I assume that’s what they were doing back then. She … certainly didn’t qualify for a one-to-one (16.1, lines 359-370).

Some caregivers indicated that because their children changed schools they missed the district cut-off date for the allocation of school-based supports. Caregivers of children who do not receive additional one-to-one support in the form of an aide but who encounter principals who are creative and flexible about support have more likelihood of reaching islands of calm. A biological mother using tactics to orchestrate schooling to provide support credits the principal with allocating a student teacher to her daughter’s class so the regular classroom teacher had more time to support her daughter:

Because she came back a quarter of the way through the year there was no funding for any extra support for her. We’re very lucky that the principal there is creative and he will go and cause himself more work because he has taken on student teachers. Because [my child] now …, even if she doesn’t get help from this [student] teacher, her regular teacher will then have maybe more time (5.1, lines 90-93; 137-139).

When children enter specialized programs, as a result of caregivers using tactics to orchestrate schooling and support from school personnel, it buys caregivers temporary respite and increases the likelihood they can spend less time and energy regulating their
relationships and keeping up appearances to be viewed as “responsible” parents. Specialized programs include: programs for children with FASD, programs for children with behavioural and emotional difficulties, and special classes. In these programs, teachers and assistants are knowledgeable about FASD, the ratio of teachers to students is lower, and the environment is structured to increase children’s chances for social and academic success.

When children are in special programs caregivers need to advocate less for resources that help children regulate their behaviours and can reduce their tactics to orchestrate schooling and be intertwined to fit in. Some participants indicate that staff members in special programs engage in preventative actions to defuse children’s behaviour before it becomes necessary to ask parents to intervene or take their children out of school. The caregivers describe staff members structuring environments to reduce sensory triggers and accommodating students’ sensory needs which make success for children more likely. One parent comments that the specialized program her child attends has a psychiatrist on staff that helps regulate her child’s behaviour and reduces the caregivers’ time and energy using tactics.

P: [The program] is good because they won’t call you and be like, “Pick up your kid.” They have isolated rooms that are like…it’s called the “Blue Room”…it’s all blue. Nothing else in there. They close the door…there’s a window…you can see in there…the kids can go crazy…break the…hit the walls…do whatever they want but they can’t hurt themselves because there’s nothing to hurt themselves with. So, they’ll be in there until they’re calm and then they’ll have a timer. If they look calm, they still get time to see if they are for surely…calm because they could just be like
playing ‘Hey…I’m calm…let me out,’ and then they go nuts again. It’s really good because they let it all out and by the time they let all that anger and all that energy, they usually have their meltdown and then they talk about what’s bothering them….

R: So you didn’t need to go in during school hours?

P: No…never (13.1, lines 205-223).

In an example of a negative case, one parent indicates the special program for her child does not offer her a temporary reprieve.

I tried sending her to a school in [name of district] that had a specialized class for children with FAS, which I thought was brilliant. Accept eight students, with four adults. But the four grade sevens were all boys, so it was six boys, two girls. They were more severely affected than [my daughter is], intellectually, emotionally, you name it. So she was really having a really hard time at that school, and I was trying to keep her there. So I’m doing the best with what’s out there, but I get the fact of integration, and I get the fact of segregation. It doesn’t always work, right (5.1, 71-88).

This participant suggests, even when the educational environment is adapted to facilitate success for students with FASD, the fit between participants in the program and difference in presenting behaviours can interfere with students’ success. Those types of conditions result in caregivers having to devote energy and time to tactics to orchestrate schooling for success for their children and keep up appearances as good parents.
The lack of stability in school programs reduces the likelihood that islands of calm will persist. Several participants indicate that when their children do better in specialized programs they are integrated back into the regular programs. Moving their children out of supportive environments can disrupt progress, offer less support for students, and increase time and energy caregivers devote to tactics to orchestrate schooling so they can stay intertwined to fit in.

Had to go in and talk to them and explain my story and why I think this would be a good program for him and they were like “yeah.” So it helped him to come. It was only for one year. I tried to push one more year but they said he was so good in his academics that he’s ready to go to [the regular program] (13.1, lines 64-68).

Caregivers who can anticipate the need for support for themselves and actively seek out support are more likely to reach islands of calm and occupy them for longer. Proactive caregivers who seek and gain support or have accessible support can maintain the time and energy required to promote success for their children and promote themselves as “good” and responsible parents. Successful tactics buy caregivers times of respite and allow them to stay intertwined with their children.

R: I have two more questions…specifically…one is if you can tell anything to other caregivers of children with FASD and other parents, what would you tell them?

P: Look after yourself.

R: Great. Can you tell me a bit more about that? What does that mean?
P: Well…these kids are draining and if you don’t look after yourself, you’re not going to make it….You know…for us as an adult, that’s a routine you have to get into, just like if you’re…whatever it’s going to be, if your hobby is going to be rock climbing or working out or whatever…whatever it is (9.1, lines 458-468).

Caregivers indicated that living in close-knit neighbourhoods with long-term connections and easy access to support and services increases their chances of reaching islands of calm and occupying them for longer. Feeling accepted in neighbourhoods makes keeping up appearances easier because less energy is devoted to tactics to be seen as “good” and responsible parents. When caregivers are also connected to support people with knowledge of FASD, orchestrating schooling through pitbulling (e.g., hauling in support) is also easier. This leaves time and energy to focus on the relationship with their children. All caregivers identified communication-on-the-go as an important condition that helps them to maintain islands of calm where their children are successful. Easy communication with the school reduces their use of tactics to orchestrate their children’s schooling and assists with staying on islands of calm. Communication-on-the-go involves informal communication beyond the usual structures for communication that typically occur for parents and school professionals (e.g., structured planned meetings). Communication-on-the-go sends caregivers a message that they are acknowledged and respected as experts on their children. They can throttle down their tactics to keep up appearances as good parents. Under conditions of growing trust that result from communication-on-the-go, both caregivers and teachers are more likely to work together to make success possible for children. A foster mother describes what communication-on-the-go looks like:
It looked like the school having that freedom to literally call me in the moment and say, “You know, we started to do this, and this happened, and now she’s doing this. I’m thinking about doing this, what do you think?” (16.1, lines 269-272).

To summarize, caregivers reach two possible critical junctures depending on whether strategies to intertwine to fit in are unsuccessful or successful in the short-term: hitting rock bottom and reaching islands of calm. Hitting rock bottom and reaching islands of calm are associated with short-term outcomes. Short-term outcomes associated with critical junctures allow caregivers to figure out where they are in terms of using their strategies and cycling back in. Short-term outcomes associated with hitting rock bottom for parents include: despair, anger, exhaustion, disconnection, and feeling drained, shunned, side-stepped, and, for biological parents, guilt and grief. Short-term outcomes for children include: either being out of school or in a holding pattern at school, frustration, feeling detached from school or resisting school, and lack of inclusion. For caregivers, hitting rock bottom indicates failure at orchestrating schooling resulting in being ignored or being marginalized as parents. Hitting rock bottom and staying there for long periods puts caregiver-child relationships in jeopardy.

Short-term outcomes associated with islands of calm for parents include: respite, time and space for personal development, tranquility, hopeful signs, and receiving support (from people or programs). For biological caregivers, short-term outcomes also include respite from guilt and grief. For children, short-term outcomes from reaching islands of calm include: being happy at school and staying in school, maintaining routines, showing more mature behaviours, and feeling included.
At the point where intertwining to fit in can come under threat, through hitting rock bottom, and islands of calm are jeopardized, through changing conditions, caregivers move out of rock bottom and from islands of calm to re-engage with the system.

5.9 Re-engaging

Caregivers who hit rock bottom or reach islands of calm that are deteriorating use advocating, educating, and changing settings to re-engage with the school system. Because intertwining to fit in goes in cycles, the caregivers are using those approaches to re-engage with their strategies of orchestrating schooling and keeping up appearances and with the “system.” Because hitting rock bottom has caregivers putting all of their energy and time into maintaining relationships with their children and reaching islands of calm generally does not persist given the lack of stability in school arrangements and children’s conditions; caregivers regard both critical junctures as temporary.

Hitting rock bottom has caregivers struggling to regulate their children’s behaviour by themselves and twenty-four hours a day, which eventually puts their relationships in jeopardy. Caregivers who are having difficulty regulating relationships and considering giving up on intertwining to fit in re-engage with the school system to leave rock bottom. When being on islands of calm (where caregivers have had respite from actively managing) is jeopardized through changing conditions caregivers recognize they must re-engage with the system.

To retain their image as “good” and responsible parents and to help their children succeed academically and socially, caregivers must begin a new cycle of intertwining to fit in and using tactics to orchestrate schooling and keep up appearances. The short-term outcomes
associated with critical junctures give caregivers information about where they are in terms of using their strategies and cycling back in.

To re-engage with the school system, caregivers use tactics, specifically, advocating and educating and changing settings which help caregivers to make transitions from islands of calm or hit rock bottom into another cycle of intertwining to fit in.

5.9.1 Advocating and Educating

After hitting rock bottom or reaching islands of calm that are deteriorating, all caregivers identified the necessity to be present and re-engage with schools so they can orchestrate their children’s schooling and keep up appearances. The caregivers have to re-establish themselves in the context of the school system. They do that through advocating for their children and educating school personnel about FASD. Caregivers use advocating to connect or to re-connect with school staff members, such as administrators, classroom teachers, special education teachers, and teacher assistants. They try to create a dialogue about their concerns and goals for their children. To be able to advocate for and educate about their children, caregivers needed to overcome doubt in their doubts about speaking as children’s parents and find their voice:

P: I’ve been a little afraid to speak up…like who am I when they’re the professionals?

R: Okay. That’s interesting that you’re mentioning that. People have alluded to that in different ways. And I’m wondering…can you tell me a bit more about that?

P: Well…it’s because they have the education…they are trained to be teachers and whatever in the educational system and I haven’t been to school for a long time…do I
know the current…what is happening right now…yeah…the current curriculum?
Teaching methods have changed in so many ways and so I’m giving the
responsibility to them…. And then finally… “No! My child doesn’t know that 7 and
1 is 8. They don’t know what to do with this! There’s a problem here!” So this is
where it started (11.1, 69-71; 82-84).

Caregivers advocate and educate by sharing their perspectives about the changes
needed for their children to achieve academic and social success and providing the system
with requirements for their children’s educational and mental health needs. Caregivers
educate personnel in the school system about the nature of FASD because they often find
teacher knowledge and training in working with children with special needs is not enough:

The SEA that we had last year was a very skilled knowledgeable person and like I
say, the one we’ve got this year is skilled and knowledgeable but in the world of
autism, not in the world of FASD; not that last year’s was necessarily FASD but she
was…she went to every workshop she could go to, to learn more. Anything I could
give her to read, she was willing to do. She was interested in finding out more and
how to work best. This year it’s not that way at all (4.1, lines 391-397).

Coming into relationships with staff members who are uneducated about FASD requires
caregivers to advocate and educate. Participants spend significant amounts of time educating
school-based professionals about the nature of FASD and their children’s strengths so their
potential is recognized and acknowledged. They position children’s weaknesses as outcomes
of brain damage rather than difficult behaviour to try to increase empathy for their children.
Their efforts at education provide the basis for interventions and changes to educational environments that promote their children’s academic and social success. For example, a participant educates the school about her child’s need for continuity, which could help prevent the child’s behaviour from setting him apart from other children to the point where he needs to leave:

That began our year with [our son], in the school every day. Every day we were there supporting him to make it work. Things that people take for granted, uniformity of language, was really important. Do you call that “dress up area” or is that “play area”? Do you call that “the toilet” or do you call that “the bathroom”? Things like that. Do you call that “dinner” or do you call that “supper”? Things like that could throw him off. We needed to really advocate, more importantly we needed to educate the school to give him a successful year. Our goals were different than their goals (8.1, lines 38-41).

Caregivers use educating and advocating to re-engage with the school system because they recognize that schools are pivotal to their children’s chances for success. They also want to change how school personnel view them as parents. A biological mother explains how her persistent educating shifted understanding of her child and how the school perceived her as a parent:

But then I think that’s when the principal finally went, “okay, wait a second. She’s not just a mom with a spoiled kid that misbehaves.” And then...because it is I guess still new, Fetal Alcohol, right. So now I’m not the big bad birth mom that’s causing the problem, I’m the big bad birth mom that’s trying… (5.1, lines 203-207).
With knowledgeable teachers and assistants, caregivers need to expend less effort to re-engage through advocating and educating. A caregiver explains scaling down her efforts at educating when her child’s teacher is knowledgeable about FASD.

When [my child] was assessed and she started to get help with the teacher’s assistant, they were lovely. This one teacher, Mrs. A, she had an FAS child herself so she knew exactly what it was all about. And so she worked really hard with [my child]…. It was a good year… (11.1, lines 92-98).

Parents identified provincial experts on FASD who support teachers, through information, training, and resources, as important in reducing their work in educating and advocating; even in those cases, they still need to keep at it. Some caregivers indicate that even when their children have been identified as a child with FASD and the school is aware of the existence of outside resources, they continue to advocate for their children and push for provincial resources.

So there’s a group called POPFASD, they are out of Prince George or whatever, and they have the…. they have to be invited by the school, but there’s always a way around that… there’s always a way to get it done (5.1, lines 588-594).

Caregivers continue to educate and advocate because they want their child’s individual needs to be recognized and to avoid hitting rock bottom.

You have to educate everybody because every FASD child is different than another one. “Oh! I had that boy and he was FASD and I know all about it.” “Yeah…well, you didn’t meet my son yet!” “Well…how come your son’s doing that?” “Cause he’s
FASD.” ”Well…the child I had didn’t do that!” “Yeah…I’ve got how many girls…they don’t all look the same. I’ve got one chunky one, one skinny one, one is average.” You know…they don’t come out the same (12.1, lines 418-424).

School personnel that are welcoming for parents increase their ease in advocating and educating through engaging in dialogue about their children with school-based professionals. Caregivers have difficulty predicting when difficulties associated with FASD will arise that require a meeting with teachers and other school based personnel. In schools where caregivers have ongoing contact with teachers, advocating is much easier:

She phoned me one day and asked me how [my child] was doing and I said, “I need to talk to you about her,” and I said, “Can you call me back?” And she got sick the next day so she didn’t call me back, but the next day she called me back…and then I saw her at the school because we go to breakfast up there and she said, ‘Well…you wanted to talk to me about your daughter and I said ‘yeah.’ (3.1, lines 171-178).

Conversely, caregivers indicate their lack of access to teachers on a regular basis and lack of being welcomed into the school, outside typical structures for consultation, make re-engaging through advocating and educating more difficult.

Caregivers indicate that support groups can provide them with information about strategic ways to advocate so they don’t get viewed as a “problem parent,” and the “right lingo” from other caregivers who parent children with FASD. Strategic use of language when advocating for children and educating personnel in the school system permits parents to advocate more successfully and increases the likelihood they would be viewed as
“cooperative” and “good” parents by the school and can re-engage their children successfully.

And you know, it’s also important that you use the right words to get an aide. So if you use words like “flight risk,” that’ll get you an aide really well. So it’s understanding their language and being able to use their language to make a case for your child (8.1, lines 289-293).

Observations, document analysis, and data from interviews indicate that, in addition to connecting to others at support groups, many caregivers indicate that when they move from rock bottom or islands of calm they seek out opportunities to connect with parents and professionals. They seek from them the kind of knowledge that they need to keep at educating and advocating so they can move back into orchestrating their child’s schooling and keeping up appearances. Some caregivers seek out networking opportunities at conferences or presentations. Lack of financial resources makes it harder to re-engage at conferences but having a support network makes it easier.

And I went to the conference in Victoria just last month…. And very lucky, I got free to go but I had to pay my own ferry, I had to pay my own room, I had to pay… I was going to go across in my van and sleep in my van, because I don’t have that kind of money. But luckily another foster mom I have met in my past said, “You know what, I was going to have someone else with me, they backed out, I still have the extra bed in my room, stay with me.” You know, it was a kitchenette. We chipped in for some food (5.1, lines 371-378).
When caregivers take stock of effects of employing tactics and strategies to reach the desired long-term outcomes for their children (e.g., success and stability), some decide to participate in research. Three of the participants in the study indicated that they perceived connecting through taking part in research as ways to gain knowledge so they can keep at educating. Those caregivers took part in the study to connect to make orchestrating their children’s schooling easier by getting information about resources. A participant who frequently attended conferences said:

But I know enough people now from going to conferences and talking with people and being very open, and maybe doing a study like this. Well who knows, in six months from now I might phone you up and go, “Do you know who…” you know, whatever, right. So this is the way I try to connect and get help for free, per se right, for my daughter and I (5.1 lines, lines 25-30).

Caregivers re-engage with schools so they can orchestrate their children’s schooling and keep up appearances. They do so through advocating and educating. Knowledge of FASD, support and welcoming school personnel influences the amount of energy caregivers direct towards re-engaging through advocating and educating.

5.9.2 Changing Settings

Changing settings is another tactic some participants use to re-engage with the “system” and begin to orchestrate their children’s schooling and keep up appearances following disengagement while at rock bottom or when islands of calm deteriorate. Changing settings involves changing schools within the same neighbourhood, changing
neighbourhoods so children can attend a new school, and for two participants, leaving the public system and entering the private system. Financial resources, the characteristics of caregivers’ neighbourhoods, power differences, and stigma all influence the likelihood of caregivers using this tactic successfully. The following quotation illustrates an example where a foster mother changed settings to re-engage with the school system after hitting rock bottom, disconnecting, and directing all her time and energy to regulate her relationship with her child:

Yeah, it’s fight or flight. And you fight, and you fight, and you fight, and there’s a point where you have no energy left to fight. So what’s the option? You flight, you’re gone. So I did the best that I could do. And my flight [to another school] was short, but I thought it might work (16.1, lines 1046-1049).

When caregivers have resources, particularly financial ones, changing settings to orchestrate their children’s schooling and keep up appearances is easier. One participant, who worked full time in the health care and education system and shared responsibilities with her partner, was able to change settings when she felt disrespected by the system:

P: I arrived at the school and they wondered why I was there. And I wondered why they were all in lingerie, because it was pajama day. And the teacher, the learning resource teacher, said to me, I thought we would cancel the meeting since you didn’t have a professional to bring with you.

R: How did you understand what she was saying there?
P: What does a professional look like was my question back to her. She might be the expert on teaching him to read or to write, but I’m the expert on my child. And there is no one greater to bring than myself and my husband. And then I began to go around and I interviewed schools. I interviewed resource teachers, I interviewed principals, I interviewed the vice superintendent, until I found a good match (9.1, lines 18-36).

Caregivers with limited financial resources are more likely to persevere with a setting rather than changing settings to re-engage. They spend more time waiting it out at rock bottom. Their challenges with financial resources are eased when they are living in a close-knit community with access to formal and informal support and where keeping up appearances was easier because caregivers felt accepted and not judged. Under those conditions, caregivers found it easier to move out of rock bottom and re-engage with schools without resorting to changing settings. Living in poverty limits caregivers’ choices (e.g., when participants wants to move to a new district where their child can attend a school where they believe fitting in may be easier for their child, but they can’t afford to move); and creates additional stress for caregivers (e.g., when they need to spend time and energy to figure out how to provide for their children’s basic needs or make hard choices between basic necessities). Caregivers with less financial resources are more likely to be blamed when their children do not fit in but cannot access alternatives. A participants remarked, “If we had a choice right now…it if I had the monetary ability, none of these kids would be in the public school program” (11.1, lines 732-733).

For two participants with financial resources to leave the public system and enter the private system, changing settings was a very effective tactic for re-engaging with the school
system. One participant entered her child into a faith-based program in a community where she had long-term connections and where keeping up appearances was easier for her. A second participant enrolled her child in a school for children with learning disabilities where a small student-teacher ratio and knowledge of FASD made fitting in easier for her child; because her child experienced some academic and social success keeping up appearances as a parent was also easier for her.

Power differences constrain caregivers from re-engaging through changing settings. When foster parents have to wait for social workers to make “judgment calls” about services and whether they can move their child to a new school re-engaging through changing settings is difficult. The caregivers’ sense of themselves as experts on their children is undermined when others make final decisions affecting their children; thus, it is more difficult to move out of rock bottom:

So what this child, who has not managed Grade Three, who has been distinctly unsuccessful to the point where I actually pulled her out of school three weeks early. And I had to fight tooth and nail to do it, because I’m not her guardian, and I had to plead my case before a social worker and a therapist and a psychiatrist to say, “It’s become so detrimental that that she’s become non-functional”…. You know, [social workers] make the judgment call. And I think that’s the frustration that a foster parent has that… I don’t have that freedom. I am dependent on a social worker to make the judgment call (16.1, lines 950-956; 1645-1648).

When caregivers re-engage by changing school settings so they can stay intertwined to fit in they have to sacrifice the goal of stability for their children in the hopes of achieving success
in a new setting. Because children with FASD react to change, giving up on stability through changing settings is likely to require caregivers to direct more of their energy to other areas of their children’s behaviour. For example, a foster mother’s continuous advocating for her child’s inclusion into a special program with knowledgeable staff and a lower student-teacher ratio increased academic success for her child but undermined the child’s friendships. Her child had to commute to a different community to attend school. In this example, she sacrificed social success for increased likelihood of academic success.

And so that particular social development program she was in was literally on the far side of the district. Like, I don’t think you…it would have been challenging to get any further apart…. The neighbourhood inclusion doesn’t happen for these kids. She’s now transported there and back every day to another neighbourhood (16.1, line 916-925).

For all participants who change settings to re-engage, leaving one school for another is always characterized by initial optimism, renewed energy and a sense that success is possible for their children. Almost all the caregivers who changed settings commented on feeling acknowledged as a parent by the new school. Because labels such as “difficult parent” have not yet been attached to caregivers when they enter a new setting, changing settings also means they don’t have to work so hard initially at keeping up appearances or being viewed in a favourable way by the school. The following two quotations illustrate caregivers’ perceptions of the new setting as a place where fitting in may be possible for their children:
I visited the (new) school and I immediately liked the atmosphere, I liked the calmness, I liked the interaction of the children. And my sense almost from walking in the door was that people were having a good time there. Not a good time so much as they were safe, comfortable, learning, and calm, and fulfilled in some way (17.1, lines 534-539).

And,

I think given the long history of the [new] school that they’ve got things worked out and even walking around there and getting the feel for the place and how they interacted with students and had a totally different feel than the [old] school (11.1, lines 807-810).

Some caregivers’ positive feelings associated with a new setting changed into skepticism shortly after changing settings. Changing settings may only provide a temporary sense that orchestrating schooling and keeping up appearances will be easier. Initial optimism after re-engaging can give way to skepticism.

R: Since we’ve spoke last, you moved to this area and maybe you can just start by filling me in about what’s been happening in terms of the schooling.

P: The fact that the principal is willing to take on the kids as a…you know, sort of as a case manager kind of person, it’s a different flavor all together and everybody in the community says to me that that school happens to be the best…. the best reputation for supporting kids that have got difficulties. Now, it will be interesting to see how it actually goes but everybody that I’ve talked to says it’s the best elementary school in
the city for kids, so hopefully it will work okay and you know, he’s got a couple of people that he’s already met… the mental health team out here is not any more accessible than it was [in the old district], so it’s going to be interesting (4.2, lines 57-58).

To summarize, caregivers move out of rock bottom and from islands of calm to re-engage with the system. To re-engage, caregivers employ the tactics, advocating and educating, and changing settings. These tactics are used by caregivers to move back into a cycle of intertwining to fit in.

5.10 Summary

Intertwining to fit in is a dynamic cycle that explains how caregivers of elementary school-aged children with FASD try to resolve their main concerns, which are preventing their children from failing academically and in social interactions, and, preventing themselves from being regarded as “bad” parents. Regulating their relationships with their children is intrinsic to intertwining to fit in. Regulating their relationships is used by caregivers to maintain their “parental” relationships with their children but to avoid becoming intertwined to the point where they deny opportunities for their children to have the independence to fit in.

The cycle of intertwining to fit in consisted of two strategies, orchestrating schooling and keeping up appearances. Caregivers use the strategies to maintain their relationships with their children and to engage with the school system in ways that permit them and their children to fit in. To orchestrate schooling caregivers use tactics, specifically being on stand-by, pitbulling, cultivating connections, and anticipating difficulties. Caregivers are engaged
in intertwining to fit in and orchestrating schooling to promote their children’s academic and social success. Caregivers used another strategy, keeping up appearances to attempt to present themselves as “good” or responsible parents. Keeping up appearances comprised tactics, of sharing information, reframing, and redefining self.

Orchestrating schooling and keeping up appearances are mutually dependent. If tactics to orchestrate schooling are repeatedly unsuccessful, caregivers perceive themselves as “bad” parents. When all of the tactics to keeping up appearances are unsuccessful, caregivers temporarily give up on using those strategies to intertwine to fit in. Hitting rock bottom has caregivers struggling to regulate their children’s behaviour by themselves and twenty-four hours a day, which eventually puts their relationships in jeopardy. If tactics to orchestrate schooling are working, caregivers view themselves and their children as reaching islands of calm. They are achieving some short-term outcomes that contribute to their children being academically and socially successful. Children who are academically and socially successful make it more likely that parents’ tactics to keep up appearances will help them to achieve the short-term outcomes which contribute to them being regarded as good and responsible parents. Putting together many islands of calm increases the likelihood that parents and their children move toward long-term “ideal” outcomes. For parents, those outcomes are within reach, in part, because when their children are succeeding all of their energy and time does not need to be invested in regulating their relationships with them.

None of the actions parents take occur in a vacuum. Conditions, such as living in poverty, availability of support, and openness of school personnel to parents as experts on their children, influence caregivers’ attempts to intertwine to fit in. Because school conditions continually change the caregivers are engaging and re-engaging in orchestrating
schooling and keeping up appearances to go through cycles of intertwining to fit in. They throttle strategies up or down as needed so that they can stay involved with their children and fit in. When caregivers perceive their relationships with their children are threatened, in hitting rock bottom or deteriorating islands of calm, they do their best to re-engage with the school system so they can stay intertwined to fit in. To re-engage, caregivers employ the tactics of advocating and educating and changing settings. These tactics are intended to help caregivers move back into a cycle of intertwining to fit in.

Caregivers’ success with employing strategies, re-engaging and regulating their relationships with their children affects the long-term outcomes they are trying to achieve. When islands of calm are strung together for longer periods of time, through caregiver actions and favourable school conditions, caregivers can use their success with short-term outcomes to move toward the ideal long-term outcomes associated with intertwining to fit in. When caregivers have some success moving towards long-term outcomes, they feel they and their children are cycling forward. Unfortunately, the nature of their children’s conditions means that stability is brief and desirable outcomes can often be placed in jeopardy. Over time, when the ideal long-term outcomes are not reached and hitting rock bottom happens frequently, caregivers have the sense they are cycling backwards and may contemplate giving up intertwining to fit in.
Chapter 6: Discussion

6.1 Introduction

In this chapter, I discuss the substantive theory in the context of the literature. I start with comparing selected concepts in the substantive theory with the extant literature to indicate the contributions of the substantive theory. I discuss limitations of the study, with a focus on constraints around the limitations associated with the development of the grounded theorist, the study sample, and the data collection strategy of participant observation. I follow this with a discussion of implications of the study. Grounded in data gathered from caregivers of school-aged children with FASD, the substantive theory has implications for school psychology practice, education, and research. I conclude the sub-section with implications for teachers and key workers. Glaser (1978) suggested that a summary of the theory is redundant and affronts the reader. Instead of summarizing the findings, I conclude the chapter with the significance of the findings for caregivers of children with FASD.

For the purpose of this discussion, I refer to the research product of this thesis as the “intertwining to fit in” model. I base my decision on Hall’s (1998) comparison of the definitions of “theory” versus “model.” She pointed out that “theory is generally regarded as a system of concepts and testable hypotheses with factual cause and effect statements.” A model, on the other hand, “consists of defined concepts that are connected to one another by hypothetical relationships” (p. 180). Because the substantive theory I developed consists of concepts linked together by hypothetical relationships, I can describe my research product as a model.
6.2 Comparing and Contrasting the Model with the Extant Literature

The cycle, intertwining to fit in, addresses important and, to date, unanswered questions identified from the FASD and school psychology literature. Specifically, the questions include: what are the main concerns of caregivers of school-aged children with FASD; how do they continuously process these main concerns; what outcomes are they hoping to achieve; and how do educational environments, educational policies, and factors such as stigma affect caregivers’ perceptions and behaviour? I developed my model in response to the aims of my study, namely to explain how caregivers of elementary school-aged children act as they try to manage their children’s schooling; contextual factors that affect caregivers’ efforts to manage their children’s schooling; and effects of contextual factors on primary caregivers’ efforts to manage their children’s schooling.

When nearing completion of writing up my theory, I used key concepts from the theory I had developed as search terms (e.g., with Web of Science and PsychInfo) to find relevant extant literature. Important to this discussion section is Glaser’s (1978) notion that a substantive theory provides comparisons and contrasts and transcends, by inclusion and integration, other theories and descriptions about an area. I focus my discussion on four main conceptualizations: intertwining to fit in; orchestrating schooling; keeping up appearances; and conditions of support. Although I integrate important conditions influencing the cycle of intertwining to fit in throughout my discussion in the first three sub-sections, I discuss support as a condition separately because of the significance of that category in my study. As suggested by Glaser (1978), other work in the extant literature becomes part of the data.
Although I chose to focus on the sections mentioned above, any of the categories in my study could potentially spur further exploration of the extant literature.

### 6.2.1 Intertwining to Fit In

The core category, intertwining to fit in, explains how caregivers continuously try to come together with their children through intertwining, and use strategies to maintain their relationships with their children and fit in the context of school structures. Central to the core category is its dynamic cycling nature, caregivers’ continuous regulation of their relationships with their children, the complementary nature of the relationship between caregivers and their children, and the conceptualization that caregivers and their children are intertwined.

Findings from my study add to the FASD literature by explaining how primary and secondary disabilities in school-aged children with FASD influence caregiver behaviour. Specifically, the caregivers described cycles of intertwining to fit in when their children’s secondary disabilities became more evident.

Researchers have emphasized the challenging nature of primary disabilities (e.g., Barr, Streissguth, Darby, & Sampson, 1990; Burd, Cotsonas-Hassler, Martsolf, & Kerbeshian, 2003; Jirikovic, Olson, & Kartin, 2008; Kerns, Don, Mateer, & Streissguth, 1997; Streissguth et al., 1994; Timler, Olswang, & Coggins, 2005) and secondary disabilities (e.g., Dufour, Williams, Campbell, & Aitken, 1994; Green, 2007); they have also described the effects of secondary disabilities on older children’s school experiences (e.g., Duquette & Stodel, 2005; Duquette et al., 2006, 2007; Rasmussen & Bisanz, 2009; Ryan & Ferguson, 2009).
Conversely, specialized programs and services and knowledgeable teachers have been linked to success for (older) students with FASD (Duquette & Stodel, 2005).

My research findings showed that societal expectations for social and emotional self-regulation in young children (a macro-level influence) (Bronfenbrenner, 2005; Goelman & Guhn, 2011), a lack of knowledge about FASD, and the resulting unsupportive educational environments (micro-level influences) (Bronfenbrenner, 2005), increased the time and energy caregivers devoted to strategies and tactics to stay intertwined to fit in. Moreover, caregivers linked their need to devote increased time and energy to intertwining with their children to school personnel’s lack of knowledge about the nature of FASD, as a brain-based disorder, and educational environments undergoing constant change and lacking structure to promote children’s chances for success. Such conditions increased the likelihood the caregivers will hit rock bottom which jeopardizes reaching the ideal long-term outcomes for themselves and their children.

The caregivers in my study described their school-aged children as experiencing primary and secondary disabilities that significantly interfered with their success at school. Primary disabilities reported by caregivers in my study included vision and hearing problems, problems with sleeping, sensitivities to the physical environment, fine and gross motor problems, medical problems, and difficulties with memory, language, communication, transitions and adaptive functioning. Streissguth (1997) refers to primary disabilities as those disabilities that reflect the central nervous system dysfunctions inherent in the FAS or FAE diagnosis. In my study, children’s secondary disabilities, or those disabilities that develop when the primary disability interacts with external factors after birth (Streissguth, Barr, Kogan, & Bookstein, 1997), were described by caregivers as behavioural difficulties, mood
disorders, and disrupted school experiences. My findings recast primary and secondary disabilities as micro-level influences (Bronfenbrenner, 2005) that not only undermine children’s long-term outcomes of academic and social success but also the long-term outcomes for which their caregivers are striving. This is an important finding that strongly supports calls for a focus on the prevention of secondary disabilities through early diagnosis, intervention, and supportive school environments (e.g., Astley & Clarren, 1999; Gurwitch, Mulvihill, & Chaffin, 2003; Malbin, 2002). Moreover, my research findings add to the FASD and school psychology literature by detailing the influence of children’s secondary disabilities on caregivers’ happiness, hopefulness, connection, recognition as a good parent, and the sense of non-parental identity.

Caregivers in my study regarded paid employment and children’s success as mutually exclusive. Only one participant was employed full-time, with several participants either not being employed or indicating they had to decline a promotion, reduce their working hours, or delay their studies because of the full-time nature of managing their children’s schooling. In the geographical area of the study raising children while unemployed, working part-time, or having reduced work hours can result in income levels that are not adequate to support a family. Several caregivers indicated they access the foodbank to provide food for their families. These findings add new information about the connection between living in poverty and children with FASD (Astley et al., 2000) to the literature. Specifically, the intertwining to fit in model highlights the “double jeopardy” of caregivers of school-aged children with FASD. Living in poverty and lack of financial resources make it more difficult for caregivers to present themselves as “good” parents; however, the full-time nature of managing their children’s schooling prevents many of them from working or even looking for paid
employment. Recognition by others that they are “good” parents and a sense of attending to non-parental identities enable them to have the energy to regulate their relationships with their children.

My findings indicate that school-aged children with FASD are dependent on their relationship with their parents to fit in. There are parallels between this finding and the extant literature on FASD which highlights the importance of environmental factors, specifically, stable homes with involved and nurturing parents (Duquette et al., 2006; Giunta & Streissguth, 1988; Streissguth et al., 1997) in lessening the impact of secondary disabilities. Nonetheless, Olson et al. (2009) concluded in their review of the informal literature and the small body of systematic studies of FASD and caregiver function, a positive and stable family environment for school-aged children with FASD is not the norm.

My findings add to the findings in the extant literature in several ways. They emphasize that, even under favorable conditions in schools, caregivers of school-aged children with FASD were instrumental in orchestrating for success for their children. My findings extend findings in the FASD literature (e.g., Duquette et al., 2006; Giunta & Streissguth, 1988; Streissguth et al., 1997) about what it means to be involved and nurturing. Even the most favourable conditions are not stable in schools over time; therefore, caregivers in my study had to re-engage and spend time and energy employing a variety of tactics to try to create the conditions to prevent long-term negative outcomes for children and themselves. My research findings emphasize that the environments in which caregivers managed were far from stable. Caregivers directly responded to constantly shifting educational environments; they also continuously moved between islands of calm (where they experienced respite, tranquility and hope) and hitting rock bottom (where they experienced despair, anger,
exhaustion and disconnection) depending on the success of the strategies they employed and the response of school personnel. The intertwining to fit in model, therefore, extends our understanding of what “stable” environments are for caregivers and their school-aged children with FASD. The model indicates that caregivers of school-aged children with FASD, despite experiencing environments that are less than stable, invest a lot of energy and time in staying intertwined with their children.

When children were in jeopardy, such as when their secondary disabilities escalated or when they were “threatened” with expulsion from school, caregivers directed their actions to be more closely intertwined with their children. When children did well, caregivers could regulate their relationships with children so there was less intertwining and their children were given more independence. The caregivers’ continuous regulation of their relationships with their children can be compared and contrasted with Bowlby’s (1969/1982) work on attachment. He described the concept of attachment as a “lasting psychological connectedness between human beings” (p. 194). He hypothesized that the attachment behaviour system, activated during times of stress or danger, promotes safety and felt security through the child’s relationship with the caregiver. Bowlby (1969/1982) focused his theory on children’s survival through maintaining close bonds to the caregiver; the intertwining to fit in model suggests that caregivers of children with FASD regarded “survival” for their children as successfully navigating the school system. My model extends Bowlby’s (1969/1982) theory by identifying tactics caregivers use to promote children’s successful development in terms of academic and social skills.

Important to Bowlby’s theory is the idea that the caregiver promotes a secure attachment relationship by being available and responsive and that these behaviours, in turn,
allow the child to explore and venture out. The early bonds between caregivers and children provide the foundation for future adaptation, mental health, and emotion regulation (Bowlby, 1969/1982; Crowell & Treboux, 1995). Although attachment theory indicates that patterns of attachment are relatively stable across time, Bowlby argued that changing attachment patterns lead to change in the quality of parent-child interactions and changes in interaction patterns will contribute to change in the relationship (Bowlby, 1969/1982; Crowell & Treboux, 1995).

In extending Bowlby’s work on attachment to school-aged children, Easterbrooks, Davidson, and Chazan (1993) examined the role of environmental risk and protective factors in 45 seven-year-old children who were at risk due to socioeconomic and/or caregiving difficulties. They found that securely attached children in the sample were less likely than insecurely attached children to exhibit behaviour problems at home and school. In an attempt to extend attachment theory and research on maltreated children to older children, Aber and Allen (1987), in a study involving children between 4 and 8 years of age, found that physical or emotional neglect or mistreatment disrupts the balance between the motivation to establish secure relationships with adults and branching out to explore the world and being ready to learn. Al-Yagon (2007), in a study involving 56 mothers and children between 8 and 11 years of age, found that maternal anxious attachment explained children’s externalizing behaviours. A growing body of literature also documents the relationship between attachment and adolescent behaviours (e.g., Allen, Aber, & Leadbeater, 1990; Marsh et al., 2003) and attachment and adult relationships (Waldinger et al., 2003). Notwithstanding these contributions, the body of literature on school-aged children and attachment is considered surprisingly limited (Kerns, 2008). Moreover, some studies (e.g., Borelli et al., 2010)
provided mixed support for the link between attachment and emotion regulation in school-aged children. My intertwining to fit in model reduces some of the gaps in the literature and extends Bowlby’s hypotheses about attachment to concepts relevant to older (school-aged) children with FASD and their caregivers. Specifically, my intertwining to fit in model suggests that caregivers of school-aged children with FASD are actively employing strategies to maintain their relationships with their school-aged children (intertwine) so they can fit in as parents and their children can fit in at school. Moreover, the model indicates that caregivers regulate their relationships with their children to put less energy into intertwining when desired outcomes are being achieved and only consider being un-entwined (or separating from their children) when desired outcomes are in jeopardy over extended periods. In other words, they work very hard at staying in relationship with their children.

My model directs attention to caregivers’ efforts to maintain attachment rather than focusing on the quality of children’s attachment. Nonetheless, the attachment picture in terms of parents’ and children’s contributions is complex. Findings about attachment in younger children with FASD suggest children who are raised in environments where parents struggle with multiple stressors, e.g., addiction issues, or where children experience multiple foster placements (Coggins, Timler, & Olswang, 2007; Streissguth et al., 2004; Stukes Chipungu, & Bent-Goodley, 2004), are less securely attached to their caregivers. For example, O’Connor et al. (2002a), in a study involving 42 mother-child dyads, found that 80% of children between 4 and 5 years of age with prenatal exposure to alcohol showed insecure attachment, compared to 36% of non-exposed children in the same high-risk sample. In another study involving young children with FASD, O’Connor, Sigman and Kasari (1992) found that mothers of infants with FASD were less responsive to their infants who
demonstrated insecure attachment relationships and showed negative affect toward them. Caregivers in my study were working hard to maintain their relationships with their children but shared their difficulties and despair when there was little sign of success. My model adds to our understanding about the potential for negative affect to develop when ideal long-term outcomes for their children are not reached.

Bowlby’s (1969/1982) theory was focused on children’s outcomes rather than the implications of attachment for caregivers. My intertwining to fit in model would suggest that caregivers of children with FASD benefit from keeping the relationship with their children intact. To be recognized as a “good” and responsible parent (i.e., keep their identities as parents intact) and to reach other long-term outcomes such as happiness, connection and self-actualization, they want to be successful at intertwining to fit in. My intertwining to fit in model extends attachment theory because it introduces strategies and tactics parents use to be regarded as “good” and responsible parents.

Caregivers’ efforts to regulate relationships with their children, through constant observation and shifting expectations, could be linked to recent work on the neurobiological basis of attachment. Atzler, Hendler and Feldman (2011) stated that maternal-child bonding is based on the co-activation of motivational mechanisms that index stress; for example, heightened vigilance and threat detection. My findings portray observation and shifting of expectations as integral to how caregivers regulate their relationships with older (school-aged) children. Caregivers in my study are constantly observing their children, observing others to determine how they are perceived as parents and their children are perceived, making sense of these observations, and re-directing their energy towards orchestrating
schooling or keeping up appearances to try to diminish threats to their own and their children’s psychological well-being and to reach desirable long-term outcomes.

When caregivers in my study perceive their relationships are threatened they put more time and energy into regulating the relationship so they can stay entwined. These behaviours were consistent regardless of caregiver type (i.e., foster, biological or adoptive parents). This finding contrasts with those of Olson and colleagues (2009) who, following a randomized control trial of 52 families of preschool or school-aged children with FASD and clinically significant behaviour problems, suggested that parents who had biological relationships (e.g., biological mothers, fathers, and grandparents) with their children reported less monitoring of their children when compared to other caregiver types. My findings add to the FASD literature by portraying caregivers of children with FASD (many who were single, biological mothers) as actively involved in their children’s schooling and continuously working towards success. This finding contrasts with stigmatized versions of biological mothers of children with FASD (Salmon, 2008) and prevailing views of lone mothers as irresponsible (Russell, 2011) and starts to address the paucity of data about the experiences of birth parents of children with FASD in interactions with the school system.

A third dimension important to my model is the complementary nature of the relationship between caregivers of children with FASD and their school-aged children. My findings add to the FASD literature because they link children’s success and happiness in school to caregivers’ positive feelings about themselves as parents. The complementary relationship between caregivers with FASD and young children has been documented in existing studies but has previously been framed in terms of negative outcomes. For example, O’Conner and Kasari (2000) found that, for mothers with more depressive features, their 5 to
6 year old daughters were more likely to report higher levels of depressive symptoms. In another study involving 42 mother-child dyads, Paley et al. (2005) found that biological mothers of children (between 4 and 6 years of age) with clinically significant levels of externalizing behaviours reported significantly higher levels of child-related and total stress than those parents whose children’s behaviour did not reach clinical cut-off scores.

My findings indicate that parents of school-aged children with FASD were more likely to regard the school system and its personnel as a threat to their children than as a support, except under the most favourable conditions. These findings concur with findings from other qualitative studies (e.g., Duquette & Stodel, 2005; Duquette et al., 2006, 2007; Ryan & Ferguson, 2006a) that indicated that families were frustrated by the lack of consistent or sufficient school-based services and add to the literature by identifying elements of the school system and personnel that caregivers regarded as unhelpful. Caregivers indicated that frequent changes in school staff, policies that are implemented differently for different students, and changes in the allocation of supports from year to year drain their energy and reduces the stability of the school environment for their children. Closed door communication policies made it more difficult for caregivers to build relationships with school personnel and to feel respected as parents.

When conditions in the school system jeopardized children’s chances for success there were far-reaching repercussions for caregivers in terms of their recognition as good parents and their long-term outcomes such as, happiness, hopefulness, and their ability to connect to others. Essentially, for children to fit in at school (be successful academically and socially) and for caregivers to fit in as parents (be regarded as a “good” parent), caregivers need to be successful at employing strategies (orchestrating schooling and keeping up
appearances) to stay intertwined while they also direct time and energy towards their ongoing regulation of the relationship with their children.

Unsupportive school environments detract from caregivers’ attempts to fit in and fit their children in. The complementary relationships for biological parents with children with FASD, means that their feelings of guilt, associated with the affected child, are less prominent when their children fit in at school. Conversely, when children are not fitting in or are unsuccessful in school, caregivers cannot prevent themselves from being regarded as “bad parents,” who do not fit in.

In terms of a question posed by Ryan and Ferguson (2006a) namely, what supports did families of children with FASD identify as helpful; my findings indicate that caregivers appreciate extra assistance for their children. They also indicate that assistants must be knowledgeable about FASD, have the knowledge to structure the environment to prevent children’s secondary disabilities from escalating, and assist children to function independently - a sign that they are moving towards outcomes of success. Characteristics of helpful programs included: knowledgeable teachers and support staff about FASD; lower student-teacher ratios; environments structured to reduce sensory triggers; environments accommodating students’ sensory needs; and open door policies where parents are welcomed inside the school.

Caregivers identified communication-on-the-go as a helpful condition. In British Columbia, according to Special Education policy guidelines (Province of British Columbia, 2011), parents are entitled to be informed about their children’s behaviour, while school personnel are advised to consult with parents in timely and supportive ways. The importance of open communication and collaboration between parents of children with FASD and school
personnel has been documented in the FASD literature (e.g., Blackburn et al., 2010; Green, 2007; Malbin, 2002); however, they are only emphasized as elements important to children’s success. My findings extend the meaning of open communication and link this important condition to positive long-term outcomes for parents; they emphasize the importance of ongoing communication between caregivers of children with FASD and school personnel. Highlighted is the importance of ongoing communication between teachers and parents over longer periods of time and the need for caregivers and teachers to find ways to go beyond the usual structures that are typically used for communication between parents and school professionals (e.g., structured planned meetings). Ongoing and meaningful communication is essential for caregivers to regulate their relationships with their children and to reconnect or re-engage with the school system. Most importantly, my intertwining to fit in model links ongoing and meaningful communication to ideal long-term outcomes for caregivers (recognition as a parent and self-actualization).

Caregivers’ main concerns are to prevent their children from failing academically and in social interactions (fitting in) and to prevent themselves from being regarded as a “bad” parent (fitting in as a parent). The foci for caregivers in this study, children fitting in at school and parents fitting in with other parents, are echoed in findings from qualitative studies documenting perspectives of parents of children with disabilities. Cohn (2001), for example, conducted a qualitative study with 22 parents of children between 4 and 10 years of age; the children had documented diagnoses of sensory integration dysfunction. Using a grounded theory approach, she explored parents’ perspectives regarding their children’s participation in occupational therapy where a sensory integration approach was utilized. All participants in Cohn’s study were concerned that their children were not “fitting in” or
“keeping up” with their peers. Although Cohn did not specify whether any children in the study were identified as being on the FASD spectrum, it is well documented in the FASD literature (e.g., Franklin, Deitz, Jirikowic, & Astley, 2008; Jirikovic, Olson, & Kartin, 2008) that children with FASD demonstrate sensory processing deficits that contribute to difficulties with adaptive functioning at home and school.

The intertwining to fit in model extends self-determination theory (SDT; Deci & Ryan, 1985, 2000, 2008). Self-determination theory highlights the innate and important drives to autonomy and relatedness and the propensity towards mastering the environment to function optimally (Deci & Ryan, 2000). A significant body of work within the self-determination theory tradition has focused on long-term goals people use to guide their activities (Deci & Ryan, 2008). Life goals such as affiliation, generativity, and personal development, also referred to as intrinsic aspirations (Kasser & Ryan, 1996), have been associated with health, well-being and performance. The caregivers in my study were striving for ideal long term outcomes of success and happiness for their children and a sense of self-actualization and relatedness (connection) for themselves. In doing so, they guided their behaviour and invested time and energy to move closer to their desired outcomes; however, they also initiated behaviour to push back against less favourable conditions in the educational environment to strive for both short-term outcomes and ideal outcomes for their children and themselves.

The intertwining to fit in model extends self-determination theory by introducing the concept of short-term outcomes. Caregivers in my study used their success with short-term outcomes to move toward the ideal long-term outcomes associated with intertwining to fit in. Reaching short-term outcomes associated with islands of calm helped caregivers persist in
their efforts to reach long-term outcomes. As pointed out by Deci and Ryan (2008), within self-determination theory, energy for action and persistence comes from actions that lead to needs satisfaction. The intertwining to fit in model, with its introduction of short-term outcomes (which help caregivers take stock of where they are in terms of long-term outcomes and reinforce efforts to move towards long-term outcomes) has the potential to contribute to self-determination theory, by providing explanations about sources of energy and vitality, which form an important aspect of motivation (Deci & Ryan, 2008).

I identified micro-to macro-level influences (contextual factors) that affected positive long-term outcomes, for example, self-actualization and connectedness for parents, and success and independence for children. Self-determination theory emphasizes the role of social context in facilitating or undermining the processes of intrinsic motivation (striving to engage in interesting activities) and internalization (the integration of values and behaviours that are important but less interesting) (Joussemet, Landry, & Koestner, 2008).

Caregivers in my study not only reflected on the importance of autonomy for their children but also reflected on the role of primary and secondary disabilities associated with FASD interacting with unhelpful school environments in undermining their children’s chances for success and independence. Integral to my study findings is caregivers’ ongoing negotiation of this tension: they constantly regulated their relationships with their children to be more or less closely intertwined. When children did well (e.g., maintained their routines, showed more mature behaviours, and felt included) caregivers could regulate their relationships with children so they could give their children more independence by focusing less on intertwining. My research findings show caregivers reflect about actively trying to support their children’s autonomy through adjusting how they intertwined with their children.
This is an important finding because autonomy support, defined as active support for a child’s capacity to be self-initiating and autonomous, is considered one of the key components of successful parenting (Landry et al., 2008; Ryan, Deci, Grolnick, & La Guardia, 2006).

Joussemet et al. (2008) link autonomy support along with acceptance and behavioural (as opposed to psychological) control to improved child adaptation and school success. Conversely, parental psychological control was shown to be positively correlated to relational aggression in a sample of 600 school-aged (8 to 10 year old) children (Kuppens, Grietens, Onghena, & Michiels, 2009), while low levels of emotional support and harsh discipline have been linked to the development of externalizing problems in school-aged children (Olson et al., 2011).

In my study, success for children and success for parents were intertwined. The complementary nature of autonomy support and success for children is reinforced by findings from a study by Joussemet, Koestner, Lekes and Landry (2005). The researchers examined the relationship between maternal autonomy support and school adjustment over time. They found that autonomy support (coded from interviews when children were 5 years old) was positively related to academic, social and overall adjustment, as measured when children were in grade 3.

My findings highlight the predicament for caregivers of school-aged children with FASD; when children’s needs for autonomy are jeopardized by school environments where children do not feel accepted and successful, caregivers have to throttle up their tactics to be more closely intertwined with their children. In cycles where tactics are not successful, caregivers’ attempts to fit in as parents and their striving for connectedness and self-
actualization are jeopardized. My findings show that children’s difficulties with regulating their behaviour are important influences on caregivers’ behaviour. Except under the most favourable conditions, children’s difficulty with self-regulation interferes with their need for autonomy and caregivers’ active support of their child’s capacity to be autonomous.

As pointed out by Joussemet et al. (2008), children’s behaviour can contribute to a parenting style that could be considered “controlling,” rather than supportive of autonomy. A controlling parenting style, used in this context, refers to the kinds of parental control that intrude on a child’s psychological world and undermine intrinsic motivation. Intrusive parenting is identified as an environmental factor that interacts with individual factors (e.g., impaired verbal skills, executive function deficits, and an imbalance between behavioural activation and inhibition systems) and plays a role in the maintenance of conduct problems in childhood and adolescence (Hill, 2002). The efforts parents made in my study to regulate their children’s behaviour, in the context of primary and secondary disabilities, show the potential for their efforts to regulate their relationships with children and to use tactics to intervene at school to engender controlling parenting styles rather than those supporting autonomy. Grolnick, Price, Beiswenger, and Sauck (2007) found that mothers of fourth graders who based their self-worth on their children’s social outcomes would be more likely to be “controlling,” and less likely to provide autonomy support. My study findings indicate that caregivers’ sense of being good parents was closely intertwined with their children’s success, which would raise the stakes for caregivers’ children to behave well.

Important to a study involving caregivers of children with FASD is findings from four studies by Landry and colleagues (Landry et al., 2008). Findings from these studies suggest that trust in organismic development fosters autonomy supportive parenting practices
and positive maternal and child adaptation. They indicated that parents, who trust that their child’s development will unfold naturally, will have less rigid goals, lower levels of stress, and feelings about themselves that are less dependent on their children’s performance. Children will benefit and show less behavioural difficulties over time.

For caregivers in my study, trust in their children’s organismic development was difficult, if not impossible. When they reached islands of calm they experienced hopefulness and positive short-term outcomes for their children. Under those conditions, they could throttle down tactics such as using stand-by 24/7, and decrease their constant observation of their children. Landry et al. (2008) pointed out trust in organismic development and optimism or hopefulness are two distinct concepts. My findings indicate that the primary and secondary disabilities associated with FASD, including difficulties with self-regulation, are powerful micro-level influences on caregiver behaviour and that trust in children’s development and hopefulness about the future are intertwined.

While, in general, the central socialization goal for children is to eventually self-regulate autonomously (Joussemet et al., 2008), children with FASD have specific impairments in self-regulation (Kodituwakku et al., 2006); my participants linked those impairments to difficulties with positive long-term outcomes which undermine autonomous self-regulation. The “intertwining to fit in” model provides insight about self-determination (Joussemet et al., 2008) by emphasizing the reciprocal nature of the relationship between parental and child behaviour and the factors that influence parents to act in controlling or self-autonomous ways.
6.2.2 Orchestrating Schooling

Caregivers in my study actively orchestrated their children’s schooling by using tactics to promote their children’s academic and social success (help them to fit in). I identified four tactics through which caregivers orchestrated their children’s schooling: being on stand-by; pitbulling; cultivating connections; and anticipating difficulties. I also identified tactics through which caregivers moved towards re-engaging with orchestrating schooling (and keeping up appearances) following a period of disengagement: advocating and educating and changing settings.

Despite facing conditions that could possibly constrain their actions, for example, ambiguous or inconsistent special education criteria for support to their children (exosystem) or living in poverty and with stigma (macrosystem), caregivers in my study described forging lines of action to respond to conditions. The findings from my study therefore demonstrate parallels with one of my guiding theories, symbolic interactionism (Mead, 1934; Blumer, 1969; Perinbanayagam, 1985). At the heart of the interactionist perspective is the issue of personal agency, which refers to the ability of people to construct and influence social reality and shape their social worlds (Sandstrom & Fine, 2003). Even when caregivers’ activities were limited by constraints of social institutions, such as schools, they showed “autonomy” by developing lines of action (Perinbanayagam, 1985, p. 53). My participants interpreted others’ actions (e.g., teachers), continuously assessed situations, and organized their actions based on those interpretations (Blumer, 1969). At times, they chose to withhold action (e.g., moderated their pitbulling through treading carefully). They throttled strategies up or down and directed and re-directed their energy and time to try and achieve success.
The findings from my study extend findings from previous qualitative studies with parents of students with FASD; those studies (Duquette & Stodel, 2005; Duquette et al., 2006, 2007) have described middle class adoptive parents as actively involved in their children’s schooling and strongly advocating for their children in the face of limited support. My findings with biological parents with school-aged children extend these descriptions because biological parents are also using the tactics attributed to adoptive parents. Furthermore, my findings recast caregivers’ efforts to advocate for their children as important tactics through which caregivers re-engage with the school system, following a period of disengagement, in order to pursue outcomes of academic and social success for their children.

My findings extend previous qualitative studies by explaining persistent and ongoing tactics used by caregivers (pitbulling and cultivating connections) as mechanisms for caregivers to orchestrate schooling to produce success for their children. Most importantly, my findings position caregivers’ active behaviours at their children’s schools as part of staying intertwined with their children and link the tactics involved in orchestrating schooling with their strategy to keep up appearances. My findings explain “what is really going on” (Glaser, 1978) for caregivers as they act in their children’s schools; their efforts to promote success for their children are linked to their tactics and short-term outcomes for keeping up appearances (being regarded as a “good” and responsible parent).

Previous qualitative studies (e.g., Duquette et al., 2006, 2007) have endpoints of description of caregivers as strongly advocating for their children in the face of limited support. These studies linked advocacy to high school students’ persistence in school. Notwithstanding the fact that early elementary school and the move to middle school are
highlighted as two important “turning points” in the life trajectories of students with FASD (Olson et al., 2009), no studies have detailed the behaviour of caregivers of school-aged children with FASD in response to the school system. The intertwining to fit in model addresses this paucity in the literature. My findings indicate that caregivers used the tactic of pitbulling to orchestrate their children’s schooling, which they described as daily battles about managing their children’s schooling. I identified sub-tactics of pitbulling, namely standing firm and hauling in support, and identified conditions under which caregivers moderated their pitbulling actions (treading carefully). My findings show that caregivers who perceived themselves as the kind of person who can stand firm and are knowledgeable about FASD are more likely to fight for what they believe is essential for their children. This finding is significant because it supports Paley and O’Connor’s (2009) recognition that caregivers may need to play a significant role in educating educational professionals and their call for interventional approaches with this population to be focused on increasing parents’ self-efficacy.

There are parallels between my conceptualization of the tactic, standing firm, and Bandura’s (1977, 1995) work on self-efficacy. The concept self-efficacy, which lies at the heart of social cognitive theory, is described by Bandura (1995) as “the belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations” (p. 2). The belief in oneself as an effective individual develops through experience and regulates behaviour (Bjorklund, 2005). According to Bandura (1995), people who believe they are competent, approach difficult tasks as challenges to be mastered rather than avoided, set high goals, and maintain commitment even when they do not succeed. Most caregivers in my study stood firm, showed commitment, and did not back down. They put
aside their fears about negative reactions to them as caregivers from school personnel and fought for what they believed was essential. When they were successful in orchestrating success for their children through standing firm, they experienced times of respite (islands of calm) where they felt “good.” Bandura (1995) purported that outcomes from high self-efficacy include personal accomplishments, reduced stress, and lowered vulnerability to depression. Conversely, people who doubt their abilities view difficult tasks as personal threats, set lower goals, and are less committed to their goals. They focus on personal deficiencies, the barriers they will encounter, and possible negative outcomes. They are more affected by stress and prone to depression (Bandura, 1995).

An important finding from my study was that caregivers who did not see themselves as able to stand firm (self-efficacious) or tried standing firm, which did not work, were able to avoid some of the possible negative outcomes (e.g., stress) by hauling in support. Hauling in support was related to the level of resources caregivers had or how connected caregivers were to their community, or both. These findings emphasize the importance of resources and support to caregivers of children with FASD in order to avoid the kinds of outcomes that could detract from desirable long-term outcomes, such as happiness, connection and recognition as a parent. They fit with the evaluative report of the British Columbia Key Worker and Support Program, wherein Hume et al. (2008) indicated that caregivers in British Columbia perceived their children to experience a variety of secondary behaviours that were both school-related and of a social/emotional nature, with 73% of the children seeking key worker services. Moreover, they fit with Coles (2003) expressed concerns about the majority of children on the FASD spectrum not meeting the criteria for a formal diagnosis and failing to qualify for services and supports.
Caregivers in my study did not merely react to situations. They engaged in self-reflection and continuously assessed situations and organized their actions based on those interpretations (Blumer, 1969). For example, caregivers were more likely to stand firm when the stakes were high or when reaching their ideal long-term outcomes was threatened; they were more likely to haul in support when the situation with their children’s schools was not so dire. When they judged their actions to be potentially jeopardizing their relationships with teachers and other staff and undermining their efforts to help their children achieve success, they throttled down their pitbulling and focused more on how they came across as parents. These findings extend the work of Bandura (1996) to caregivers of children with FASD. Bandura (1996) recognized that additional cognitive determinants, including outcome expectations, proximal and distal aspirations, and perceived situational and socio-structural impediments, operate together with perceived self-efficacy. He proposed that as self-reflective capabilities develop, people rely less on external guidance and more on self-efficacy judgment.

Two additional tactics that were used by caregivers to keep their children’s difficulties from escalating at school and keep the relationships with their children going were anticipating difficulties and cultivating connections. These findings show parallels with the research on proactive coping. Where traditional or reactive coping is seen as risk management, proactive coping is seen as oriented towards the future with a focus on goal management (Greenglass, 2002). Sohl and Moyer (2009) pointed to two differing conceptualizations of this concept. They pointed to the definition of Schwarzer and Taubert (2002) who defined proactive coping as a method of assessing future goals and setting the stage to achieve them successfully. In contrast, Aspinwall and Taylor (1997) defined
proactive coping as a process through which one prepares for potential future stressors, possibly averting them altogether. When caregivers in the current study anticipated difficulties that could jeopardize their children’s success in school, making intertwining with their children more difficult, they directed their energy in two ways: almost all caregivers worked hard at setting a positive tone in the morning to increase the chances that they would prevent failure for their children and some caregivers also tried to be pro-active and focus on setting up back-up plans at school to prevent difficulties from arising in the future. They were trying to increase the likelihood that their children would fit in.

When caregivers cultivated connections, they focused on building relationships over time with others at their children’s schools and in their communities to promote academic and social success for their children. These actions helped caregivers to overcome systemic barriers (i.e., lack of service and support), which could result from a lack of assessment or diagnoses for their children. Given that many children prenatally exposed to alcohol are not diagnosed before school entry, (Turner, 2006) this finding illuminates how caregivers push back against structural conditions that could detract from their ideal long-term outcomes. All of the children in my study were identified as on the FASD spectrum, with 9 of the children meeting criteria for a FAS diagnosis; however, Coles (2003) purported that the majority of children on the FASD spectrum do not meet the criteria for a formal diagnosis and fail to qualify for services and supports. Identifying tactics through which caregivers are able to navigate systemic barriers (supports and services) to achieve success is important.

The ideal outcomes caregivers were seeking through their purposeful attempts to cultivate connections were success for themselves and their children. Both sub-tactics (setting a positive tone and setting up back-up plans) and the tactic of cultivating connections
show similarities to Schwarzer and Taubert’s (2002) definition of pro-active coping. Caregivers essentially set the stage for success for their children, which affected their success as parents.

The fourth tactic caregivers used to orchestrate their children’s schooling was being on stand-by. Through being on stand-by, caregivers were ready to intervene to protect their children from fallout arising from frequent medical concerns and their children’s behaviour, which jeopardized their ability to be successful at school. Parents used the tactic, being on stand-by, to parachute in to take their children out of school when they got into difficulty. The tactic being on stand-by has parallels with Aspinwall and Taylor’s (1997) definition of proactive coping as a process through which one prepares for potential future stressors, possibly averting them altogether. This form of orchestrating schooling adds a component to the FASD literature and illuminates links between living in poverty and children growing up with FASD. For the participants in this study, using this tactic almost prohibited paid work. Excluding or diminishing paid work is particularly poignant because poverty and substance abuse together increase children’s risks that exposure to alcohol will be expressed as significant deficits (Rasmussen et al., 2008) and they will eventually enter foster care (Stukes Chipungu, & Bent-Goodley, 2004). In a study measuring students' proactive and preventive coping, as well as optimism in anticipation of an upcoming exam, Sohl and Moyer (2009) found that aspiring for a positive future rather than preventing a negative one predicted well-being.
6.2.3 Keeping Up Appearances

Keeping up appearances is one of the main strategies through which caregivers in my study attempted to stay intertwined with their children to fit in. The strategy, keeping up appearances, refers to the conscious actions caregivers take to promote themselves as “good” and responsible parents so they can fit in with other parents while attempting to stay intertwined with their children. Regardless of whether they were biological mothers, adoptive parents, foster parents, or grandparents, caregivers indicated that the invisible nature of FASD, the unpredictable nature of their children’s behaviour, and the lack of knowledge about FASD reduced the understanding of school personnel regarding their children’s behaviour, which resulted in the caregivers being blamed. While the FASD research has documented biological caregivers’ struggles with stigma and blame (e.g., Hume et al., 2008; Salmon, 2008), my research findings add other types of caregivers (i.e., adoptive and foster parents) to the group contending with judgment and blame. My findings also indicate the importance to biological mothers to be seen as “good” and responsible, which contrasts with stigmatized views of these parents (Salmon, 2008).

There are parallels between my findings and many concepts from symbolic interactionism. Mead (1934) pointed out that the self is the product of the mind’s perceptions of social symbols and interactions. Cooley (1922/1992), in his famous formulation of the “looking glass self,” wrote that “a self seems to have three principal elements: the imagination of our appearance to the other person, the imagination of his judgment of that appearance; and some sort of self-feeling, such as pride or mortification” (p.184). The main idea of Cooley’s looking glass self is that people define themselves and form judgments of
themselves based on society’s perception of them. Caregivers in my study portrayed their perceptions of others’ views of themselves, specifically teachers, principals, key workers, physicians, and members of support groups, formed judgments about themselves based on these imaginary observations, and then defined themselves.

Holstrom, Karp, and Gray (2011) argued that children may be one significant mirror in which parents see themselves reflected and that their children’s successes and failures would influence how they are evaluated by significant others. My study findings concur with their argument; by promoting academic and social success in school and in social interactions for their children, caregivers felt they would be regarded by significant others as a “good” or responsible parent and saw themselves that way. These perceptions of themselves are formed within the context of social processes as they act and interact with others in their children’s school environments and in their communities and by the meanings they attach to those interactions.

The findings of my study concur with studies with parents of children with other disorders. For example, in the context of Attention Deficit Hyperactivity Disorder (ADHD), Bennett (2007) examined the interplay between medical discourses and mothering subjectivities and concluded that female caregivers of children with ADHD are positioned and judged in accordance with their children’s behaviour. Moreover, Bennett (2007) found that when things go well, both caregiver and child are able to adopt favourable subject positions. When things go wrong, the opposite applies.

When comparing the experiences of 22 mothers of children with a visible disability (cystic fibrosis) to the experiences of 22 mothers of children with an invisible disability (ADHD), Cronin (2004) concluded that caregivers of school-aged children with hidden
disabilities viewed the hidden nature of the disability as undermining their attempts to avoid being viewed as a “bad” parent. The mothers of children with ADHD reported distress because their children did not easily conform to social standards (fit in), and they were more likely to express exhaustion in their roles as "mother." They also reported comparatively little family support, high perceptions of child-related demands, and doubts about their success in mothering their children, compared to parents in the visible disability group. Some of the caregivers in my study indicated similar difficulties; the lack of understanding about FASD precluded them from relying on extended family and child care support, which made time for their self-care very difficult if not impossible. Similarly to caregivers in Cronin’s study, my participants experienced exhaustion and questioned their success in parenting. More seriously, when hitting rock bottom they questioned their roles as caregivers to the point of potentially being untwined from their children.

Caregivers in my study indicated that FASD continues to be misunderstood in schools, resulting in their children often being seen as willfully misbehaving. Under conditions of inadequate support, they vigilantly fought for support and understanding for their children and to prevent themselves from being regarded or blamed as “bad” parents. My caregiver’s actions show parallels with those of parents in Ryan and Ferguson’s study (2006a); families were frustrated by the absence of community and school-based services and/or lack of consistent or sufficient services for children with FASD and made persistent attempts to find sufficient services for their children. Blum (2007) concluded that, in an era dominated by brain research, mothers raising children with invisible disabilities of a social, emotional, or behavioural nature were less likely to be blamed for causing their children’s behaviour but more likely to be blamed if they did not work unrelentingly to resolve their
disabilities. She also described mothers as positioning themselves as “vigilantes” within the educational and medical systems as a response to cost containment. My findings contrast with Blum’s findings, because biological mothers of children with FASD continue to experience blame for their children’s disorder and blame themselves for their child’s disorder.

The intertwining to fit in model links experiences of despair, exhaustion, guilt, and shame to caregivers’ attempts to manage their children’s schooling. To avoid being viewed as a “bad” parent, participants in my study were continually trying to keep up appearances by employing tactics, such as sharing information, reframing, and redefining self, while they simultaneously orchestrated their children’s schooling and regulated relationships with their children. There are parallels between my findings on the tactics caregivers use to keep up appearances and the coping literature. Coping refers to “cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands and conflicts” (Folkman & Lazarus, 1980, p. 223). There are different ways to categorize coping strategies, including problem-focused, emotion focused (Lazarus & Folkman, 1984), meaning focused (Folkman & Moskowitz, 2004), and active or passive/avoidant (Shaw, 1999). Active coping strategies are aimed at confronting problems directly and determining possible solutions to reduce the effect of a given stressor. Passive/avoidant coping refers to behaviours that are aimed at escaping the source of distress without confronting it (Folkman & Lazarus, 1984).

Comparing tactics used by the caregivers in my study with Folkman and Lazarus’ terminology, tactics of sharing information, reframing, and redefining could be viewed as active coping strategies, which are influenced by conditions of support (i.e., knowledgeable
key workers, go-to persons, and support groups). For my participants, support groups could assist caregivers to learn the tactics that helped them to keep up appearances.

One of the tactics caregivers use to keep up appearances and avoid hitting rock bottom is reframing. They reframe relationships and their children’s behaviour and biological parents reframe the assessment process. When caregivers reframe, they change the meaning they attach to the behaviours of others. As pointed out by Kim, Han, Shaw, McTavish and Gustafson (2010), positive reframing has been discussed as a type of active coping strategy in the literature, and is negatively correlated with emotional distress, while self-blame has been described as a passive coping strategy, with a positive correlation to psychological distress.

Living in poverty and experiencing stigma made using all of the tactics to keep up appearances more difficult. While no official measure of poverty in Canada exists, the term is typically used to define living without adequate financial resources to meet one’s needs (Ivanova, 2011). The use of measures of poverty, such as the Low Income Cut-Offs (LICO) and Market Basket Measure (MBM) (Statistics Canada, 2011) have been criticized by advocacy coalition groups (i.e., First Call, 2011) for failing to capture the reality of many families living in “poverty.” In my study, five participants, all single parents, indicated that they were receiving “welfare,” “income assistance,” or “disability payments.” It is estimated that only 60% of basic living expenses of single parents in British Columbia are covered by income assistance payments (First Call, 2011; Russell, 2011). Four of the participants on income assistance also indicated that they accessed the food bank to provide food for their families. Caregivers indicated that they struggled to meet their basic needs: adequate housing, food, and clothes. Poverty and stigma could be conceptualized as macrosystem
(Bronfenbrenner, 2005) influences, which affected how caregivers in my study accessed support and regulated their relationships. When caregivers were living in poverty, they were more likely to be blamed when their children did not fit in at school and it was more difficult for them to promote themselves as “successful” parents or to access “extra” resources to assist their children.

As pointed out by Russell’s (2011) review of the literature (including to name a few, Roseneil & Mann, 1996; Swift, 1995), being a single mother living in poverty already increased the risk of being labeled a “bad” mother. The caregivers in my study were also less likely than caregivers with financial resources to “access” a different, less stigmatized diagnosis, such as ADHD, and to be able to change settings when they re-engaged with the school system. These findings emphasize the “double jeopardy” some of the caregivers in my study faced as poor, single, biological caregivers of children with FASD. Ryan and Ferguson (2006a) indicated that families were frustrated and overwhelmed by the challenging behaviours of their children with FASD and described the consequences for parents’ emotional well-being resulting from persistent attempts to find services for children. My findings emphasize the trade-offs between caregivers using a lot of energy and time to promote themselves as “good” or responsible parents and having energy and time to stay intertwined with children to reach desirable long-term outcomes. Conditions of support could potentially reduce stigma associated with being a caregiver of a child with FASD. Having access to supportive relationships, characterized by trust, made keeping up appearances easier for my participants, provided that support people were knowledgeable about FASD.

Power emerged as a macro-level condition (Bronfenbrenner, 2005) that influenced keeping up appearances for parents and reaching desirable long-term outcomes. Dennis and
Martin (2005) emphasized the ways in which power relationships are enacted in schools, with long-term outcomes for children. They pointed to research (e.g., Rist, 1970) that underlines the way interpersonal processes (e.g., teachers’ expectations) contribute to a class-stratified society. My research findings, based on caregivers’ perceptions, indicate that power is enacted between teachers and caregivers of children with FASD, which not only affects long-term outcomes for children (success and happiness), but also long-term outcomes for caregivers’ parental and non-parental identities. For example, when caregivers are shunned by teachers, they are less able to exercise agency and orchestrate success for their children. My findings also indicate that conditions at schools are fluid and that caregivers actively contribute to changing conditions. When power relationships are democratized, because caregivers purposefully invest in the kinds of relationships that will lead to ongoing and meaningful communication, long-term outcomes of success for parents are more likely.

Foster parents in my study indicated they felt like second class citizens who had to rely on external authorities for decisions about their children. The effects of power relationships, on caregiving strategies, have been documented in the FASD literature. In one study, 63 licensed foster parents in a central Canadian province confirmed they would consider ending a placement if they did not receive respite care (Brown, Bednar, & Sigvaldason, 2007). The foster parents described feeling taken for granted, having insufficient information about the children, or caring for children with serious behaviour problems. My study findings illustrate effects of power on foster parents’ actions in terms of their children’s schooling and their long-term outcomes.
6.2.4 Conditions of Support

The findings from my study indicate that conditions of support were critical to caregivers reaching or approaching their long-term outcomes of success. Caregivers who were connected to supports in their communities, where they were given opportunities to redefine and reframe themselves, were able to reposition themselves as experts in their interactions with school personnel; in other words, they acted in ways that denoted a sense of self-efficacy. The implementation of provincial parent support and key worker programs (Province of British Columbia, 2007) emerged as important conditions that influenced caregivers’ efforts to stay intertwined with their children to fit in and reach their overall outcomes of success. The programs helped caregivers keep up appearances and orchestrate their children’s schooling. The existence of these programs did not guarantee that caregivers would be able to reach or approach the long-term outcomes of academic and social success for their children, happiness for themselves, and images as “good” parents; caregivers indicated they had to invest time and energy (e.g., through cultivating connections and hauling in potentially helpful supports) to create the kinds of conditions where their children could potentially benefit from these resources. Caregivers stressed the importance of the enduring relationships characterized by trust and understanding, which they formed with others in their communities and groups and which made it easier for them to keep up appearances. These social networks emerged as important influences on the long-term outcomes of success for themselves and their children.

There are points of similarity between my findings about conditions of support and the literature on social capital as explicated by Coleman (1990) and Putnam (2000). The
term, social capital does not have a single, uncontested meaning (White, 2002); however, in its present form and associated meanings it was popularized, among others, by Bourdieu (1983), Coleman (1990), Granovetter (1983) and Putnam (2000). While definitions of social capital and applications in the sociology literature revolve around the benefits of social relations and networks outside of family networks (Claridge, 2004; Portes, 2000), negative outcomes have also been documented (Woolcock & Narayan, 2000).

Entering the debate about the meaning, application, and range of effects of social capital is beyond the scope of my discussion; however, helpful relationships and close-knit communities emerged as important influences for caregivers in my study. These concepts are synergistic with the ideas of Coleman (1990) and Putnam (2000). Coleman (1990) focused on social capital as existing in relationships, while Putnam (2000) focused on social capital as existing as a resource in the community.

Caregivers in my study indicated that long-term relationships characterized by understanding of FASD and trust assisted them in employing the strategies and tactics they needed to intertwine to fit in. Stable and continued relationships affected hitting rock bottom (and caregivers’ and children’s well-being) and helped caregivers to re-engage where they moved from rock bottom into orchestrating schooling and keeping up appearances. They shared common bonds with others in their support groups for parents of a child with FASD. It is within those relationships that they felt affirmed as parents, received informational support, and learned from others the tactics to help their children succeed academically and socially. These findings concur with both Coleman (1990) and Putnam’s (2000, 2007) claims; they considered stability and continuity of social relationships as important for social capital. Putnam, who also focused on norms of reciprocity, empathy, and trustworthiness that
exist in social networks (Putnam, 2007), argued that social capital improves well-being through allowing people to resolve problems cooperatively and achieve their goals through the flow of information that exists in social networks.

My findings extend the work on social capital (Coleman, 1990; Putnam, 2000, 2007) to caregivers of school aged children with FASD by indicating that caregivers of children with FASD not only benefit from social capital existing in relationships and in their communities but also benefit from social capital arising from purposefully build relationships over time with others at their children’s schools and in their communities. The participants built those relationships to promote academic and social success for their children so they could reach their short-term (e.g., respite, attending to self) and long-term (success and happiness) outcomes. This premise that “my connections can help me” (White, 2002, p. 260) offers synergy with Coleman’s (1990) conceptualization of social capital as existing between individuals who establish relationships to generate short- and long-term goals.

With regard to social capital at the community level, all but one participant living in a setting that had been portrayed over the long-term as a community of people living in poverty and experiencing marginalization indicated that characteristics of their neighbourhood contributed to them intertwining to fit in. They described their community as “close-knit,” trusting, accepting and stable, with continuous relationships over time. Caregivers also referred to the accessibility of support for both them and their children and the flexible criteria that made it easier for them to access the kinds of supports that helped them stay intertwined to fit in. These findings are significant because they contrast with information about the “stigmatized gaze” (City of Vancouver Planning Department Community Services Group, 2009; Ley & Dobson, 2011; Masuda & Crabtree, 2010) of this
community, which emphasizes homelessness, unemployment, addiction, crime, and mental illness.

The phenomenon of geographic accessibility to support also played a role for the caregivers in my study. Social capital theory assumes that physical proximity and residential stability are prerequisites to social capital (Magdol & Bessell, 2003). Other factors, such as living in close proximity to services and existing social networks, have also been seen as important. Because caregivers in my study actively participated in support groups where they had opportunities to reflect on themselves and reframe themselves, they can be viewed as actively co-constructing their own selves, rather than being passive recipients of supports (Gibson & McKay, 2001).

6.3 Limitations

The model that was developed could be considered, to quote Glaser and Strauss (1967), “a reasonably accurate statement of the matters studied” (p. 113). Inevitably; however, all investigations are plagued by constraints, including those of skill and time (Glaser, 1978). The current study had several limitations which included the developmental nature of the grounded theorist’s skill, the study sample, and the data collection strategy of participant observation.

6.3.1 Limitations with Regard to the Developmental Nature of Grounded Theorist’s Skill

Skill in doing grounded theory develops over time (Glaser, 1978; Suddaby, 2006). Creativity and skill in memo writing, or learning to lift the data from a descriptive to a conceptual level, for example, are skills that must be learned. I used strategies to work at a
conceptual level from the beginning by following the procedures outlined by Glaser (e.g., questioning what the data is a study of rather than merely describing); however, in retrospect, I could see that initial open codes were at a lower level of conceptualization than later open codes. My process of fully developing memos also improved gradually. Fully developing my memos from the beginning of analysis could have resulted in a more complex and rich theory because more fully developed memos would have generated more ideas, grounded in data, which would point the way for theoretical sampling and fleshing out categories with more properties. While I met criteria for parsimony through re-writing the findings chapter several times, the elegance and straightforwardness of the findings (Cutcliffe & Harder, 2009) are also intertwined with the skill of the researcher.

With regard to the constraint of time, it is possible that further theoretical sampling would have added more properties that would explain the cycle of intertwining to fit in. Part of the research process involves progressing as a graduate student towards obtaining a degree within a specified amount of time. While I saturated most categories through the process of theoretical sampling and stopped sampling when I felt confident that the emerging theory explained most of the variability in the data, with more time, some categories could have been further developed. Suddaby (2006) pointed out that recognizing indicators of saturation depends partly on the researcher’s experience and expertise. This limitation should be viewed against Glaser and Strauss’ (1967) contention that “theory is not a perfect product but an ever-developing entity or process” (p. 32).
6.3.2 Limitations with Regard to the Study Sample

The study consisted of participants who were interested in taking part in research and able and willing to talk about how they managed their children’s schooling. Interest was evidenced by 14 participants’ willingness to meet to review their original transcripts and the willingness of all of the participants contacted for second interviews to meet. My findings indicated that all caregivers cycled through times where they disengaged from others. While caregivers in this study spent variable lengths of time hitting rock bottom, they also employed tactics to re-engage and move out of rock bottom. My sample may represent caregivers who were more involved in their children’s schooling and who employed tactics to stay actively involved than those respondents who chose not to participate. It is possible that a group of caregivers of children with FASD who have disengaged while staying at rock bottom would not consent to taking part in a study.

Olson et al. (2009) concluded, in their review of the informal literature and the small body of systematic studies of FASD and caregiver function, that a positive and stable family environment for school-aged children with FASD is not the norm. As per my inclusion criteria, caregivers in unstable living situations were not included. Unstable living situations could occur due to medical problems that require children to be hospitalized, the severe emotional, behavioural and/or physical problems that put children at risk for residential care, or severe mental health difficulties in caregivers.

The study sample is limited with regards to ethnic diversity. Six participants identified themselves as Aboriginal, one participant identified herself as Filipina, and ten participants identified themselves as Caucasian. As pointed out by Hall (1998), limited
numbers of participants from diverse ethnic groups could raise the possibility that subtle differences could be filtered through the researcher’s cultural bias. Along these lines, Olson et al. (2009), in their review of the literature on FASD and the family pointed out that cultural contexts shape the meanings that families place on disabilities, which in turn, affect caregivers’ behaviours. The findings are therefore limited in their applicability to people of similar cultural background to those in the thesis.

Most of the participants sampled were connected to either key workers or support groups. Recruitment of caregivers not connected to either key workers or support groups proved to be difficult. Snowballing techniques did not result in participants who were not connected because caregivers tended to nominate people they knew from groups they attended. Given that conditions of support played an important role in helping caregivers overcome stigma so they could engage in tactics, it is possible that fear of stigma might have prevented caregivers, and in particular, biological parents, from participating in a study where they had to potentially share information that could have jeopardized their attempts to present themselves as “good” parents.

In addition to these constraints, my investigation is limited by the number of participants recruited. The number of participants has not been regarded as important in a grounded theory study because saturation predicts when to stop sampling. Nonetheless, the number of incidents in a data set is limited by the nature of the participants (Hall, 1998); therefore, important components might have been missed. Including more foster parents through theoretical sampling could, for example, have added to an explanation of the influence of power differences on using orchestrating schooling and keeping up appearances to stay intertwined.
Most participants in this study were single and female. Only one male participant was included. Although I attempted to sample more fathers and two-parent families, I was not successful. Theoretically sampling of these groups had the potential to add more properties to the categories; however, Glaser (1978) argued demographic variables should not be assumed to contribute to the variability of incidents.

It is critical to take into account that keeping up appearances is an important strategy through which caregivers attempt to resolve their main concerns. One of the sub-tactics caregivers employed to keep up appearances is withholding information. Notwithstanding the tactics I employed to make caregivers feel comfortable, given their central concern was avoiding being regarded as a “bad” parent and the importance of staying intertwined with their children, it is possible that they chose not to share some information.

6.3.3 Limitations with Regard to Participant Observation

My 25 hours of participant observation was limited to observations in participants’ homes and other locations where I interviewed them. Notwithstanding the fact that I observed interactions between caregivers and their children in their homes, which added to my interview data, a limitation of this study is the constraints on participant observation. I did not, for example, have the opportunity to observe participants interacting with teachers in schools. Porter (as cited in Seaman, 2008) argued that constructing a theory about multilayered social situations requires a clear picture of the interactions of individuals, which can emerge only through the utilization of close observational techniques.
6.4 Implications for the Field of School Psychology

Sandelowski (1993) argued that the task for scholars in practice-oriented disciplines is to find ways to apprehend and represent phenomena in a way that knowledge can be advanced and practice influenced. Practice implications based on concepts and their relationships should not be viewed as tested cause and effect relationships, but rather suggestions about how the theory could be used (Glaser, 1978; Hall, 1998). In the next subsection, I suggest implications for school psychology, with an emphasis on school psychology practice, training, and research.

6.4.1 Implications for School Psychology Practice

Over time, the scope of practice for school psychologists has broadened to include a focus not only on individual students but also on the wider school system (French & Mureika, 2002; Province of New Brunswick, 2001). School-based consultation, for example, is listed as a critical competency for school psychologists (Canadian Psychological Association, 2007; Ysseldyke et al., 2006) with the potential to expand the traditional role of the school psychologist beyond that of assessing and diagnosing individual students.

Several models of consultation have been developed over the years to guide practice in the field. For example, the mental health consultation model (Caplan, 1970; Caplan & Caplan, 1999), the behavioural consultation model (Bergan & Kratochwill, 1990), and more recently, Erchul and Martens’ (2010) indirect, integrated model of school consultation have been used. The goal of school-based consultation, as guided by these models, is “to improve a client’s functioning in the school setting” (Hazel, Laviolette, & Lineman, 2010, p. 3). In describing the unique role of school psychologist in Canadian schools, French and Mureika
(2002) emphasized the role of school psychologists in working with parents (and school-based personnel) to improve students’ functioning in schools, homes, and the community. Parents are recognized as important partners in their children’s education (Province of British Columbia, 1995, 2011); however, the emphasis in current school psychology practice lies with helping to orchestrate success for the individual student.

My intertwining to fit in model alerts school psychologists to consider the complementary relationship between success for children and success for parents. Moreover, it emphasizes the need to focus on caregiver, as well as children to promote success. Such a focus would stress the need for school psychologists to consider the concerns of caregivers more directly and the conditions that allow caregivers of school-aged children with FASD to reach short- and long-term successful outcomes. Such a focus would be in line with definitions of “balanced” school psychology practice that includes prevention, consultation, systemic interventions, and treatment for chronic and severe developmental problems (Province of New Brunswick, 2001). Because outcomes of keeping up appearances affect the caregivers’ actions to orchestrate schooling for success for their children (e.g., when caregivers are unsuccessful at promoting themselves as “good” parents, they would be more likely to disengage from the school) trying to improve a student’s functioning in the school system requires psychologists’ attention to the kinds of conditions that would allow caregivers to reframe and redefine themselves as caregivers in a positive way.

Because my intertwining to fit in model explains caregivers’ behaviours and alerts professionals about the ongoing concern of caregivers to present themselves as “good” and responsible parents through the tactics they employ, caregivers’ behaviours could be interpreted in a more positive way. School psychologists, trained as scientist-practitioners are
in an ideal position to use my model to guide recommendations and interventions that involve children with FASD and their families. School psychologists could use the conditions explicated in the model that make intertwining to fit in easier for caregivers by applying this knowledge in their formulation of recommendations to schools.

An important aspect of the role of the school psychologist is to link parents with appropriate agencies and professionals outside schools (French & Mureika, 2002). The intertwining to fit in model alerts school psychologists to the importance of the lives of caregivers of school-aged children with FASD. Specifically, the model emphasizes the potentially helpful nature of support groups, connections to key-workers, and long-term connections. It also alerts school psychologists to the importance of considering the influence of stigma on caregivers’ behaviours and the importance of facilitating contexts that would make it easier for caregivers to obtain assessments and connect with others around their children’s difficulties. Obtaining assessments seemed critical for caregivers to take action and for schools to do their part and implement necessary supports.

With regard to gathering of background information to guide their assessments, school psychologists should be aware that caregivers carefully and deliberately share or withhold pertinent information in attempts to keep up appearances as “good parents.” School psychologists use structured behaviour rating systems where they rely on parents’ reports to assess psychological and neuropsychological constructs (Gioia, Isquith, Guy, & Kenworthy, 2000). The use of rating scale systems, completed by parents, is also an important part of the comprehensive assessment of the various domains of functioning for children with FASD (Chudley et al., 2005). School psychologists may, for example, use the Behavior Rating Inventory of Executive Function (BRIEF; Gioia et al., 2000), to assess executive function

As outlined in administration manuals of rating scale systems, school psychologists are instructed to “ideally” let parents complete rating scales in quiet or controlled settings, review information for missed items, and then clarify with the parent any ambiguous answers. Clinicians using the Vineland Rating Scale (Sparrow, Cicchetti, & Balla, 2005) format, for example, are encouraged to ask parents to read instructions and complete the rating scale; however, assessors are also advised to provide additional instruction to parents where necessary. The use of the Vineland Interview Form (Sparrow, Cicchetti, & Balla, 2005), an alternate way of data gathering, is encouraged when participants are anticipated to show distress when reporting on their children’s deficits. Such an approach would be supported by my research findings. My findings indicate that caregivers were distressed when their children experienced difficulty. An interview format would allow parents to also elaborate on their children’s strengths and assist them in keeping up appearances. Another measure, the Adaptive Behaviour Assessment System (ABAS-II; Harrison & Oakland, 2003) is considered easier to administer than the Vineland, and, based on anecdotal reports from clinicians in the FASD field, correlates well with observation (Chudley et al. 2005). The ABAS-II allows for less flexibility in administering items to parents. My model suggests caregivers of school-aged children with FASD tend to share information under conditions of growing trust, which suggest that face-to-face contact in administering parent rating scales would be optimal. Given the importance of conditions of trust for caregivers, my research
findings support the use of face-to-face administration of rating scales in interview format, where possible. My findings point to psychologists considering the advantages of using tools to assess students with FASD that allow for face-to-face or semi-structured interviewing in their decision making about appropriate instruments.

As pointed out by Chudley and colleagues (2005), readily available tests measuring the various domains of functioning are often not sensitive to real life issues or are considered to be inadequate to tap the kinds of social and adaptive difficulties experienced by children with FASD. Adequate testing appears to be an important area that needs further research. My findings highlight the importance of interview formats in test construction that would allow clinicians to not only access the kinds of in-depth information needed to inform diagnostic decisions, but also to set the stage for caregivers to be comfortable to share information and reframe themselves in positive ways. Modifications to testing, where possible, may especially be pertinent when working with biological families of children with FASD, who seemed to experience considerable guilt.

The intertwining to fit in model also indicates that caregivers can contribute to staff turnover, by relying too heavily on teacher assistants to regulate their children’s behaviours, with the teacher assistants getting burned-out. School psychological services include the provision of consultation services to school and district staff concerning issues such as personnel stress, burnout, anxiety and depression and referrals to outside professionals where needed (French & Mureika, 2002).

My model emphasizes the need for teachers and staff to understand FASD. Part of the role of the school psychologist is to help the system as a whole to improve its effectiveness in helping students with mental health and learning difficulties (Canadian Psychological
Association, 2007). School psychologists could provide district-wide in-service training to staff to alert them about important concepts contained in the model and increase their knowledge about effects of prenatal alcohol exposure.

The intertwining to fit in model identifies the tactics and sub-tactics caregivers employ to keep up appearances. Initial parent interview meetings, consultation meetings with parents, and assessment feedback meetings could be used by school psychologists to give caregivers opportunities to reframe, redefine, and share information. Such a focus would move school psychologists into an “interventionist” (Flanagan, 2011) role where they are focusing on concerns above and beyond those articulated in the initial reason for referral. As discussed by Flanagan (2011), the role of the school psychologist in offering targeted interventions during relatively brief meetings with parents represents complex professional situations for which there is currently no guiding literature. My model provides a helpful framework that could sensitize school psychologists involved in consultation with caregivers of school-aged children with FASD. Psychologists can use the model to identify potential concerns and salient conditions that influence caregiver behaviour and outcomes, with caregiver feedback about the relevance of such areas for them. Indeed, as Sheridan and Gutkin (2000) pointed out, school psychologists, who typically have the most mental health expertise of all professionals working in schools, have an ethical responsibility to focus their practice on broader problems than those of assessing and diagnosing students.

School psychologists who work outside schools (e.g., in mental health settings), where they engage more frequently in consultation and therapy, would have additional opportunities for intentional practice as interventionists sensitized by models, such as my intertwining to fit in model. Recognizing that such practice necessitates clinical skills not
typically addressed in school psychology training, I have indicated implications for training in the next section.

6.4.2 Implications for School Psychology Training

Training in consultation is recognized as an important component of professional psychology programs (American Psychological Association, 2008). My model emphasizes teaching models that expand on traditional consultation models by focusing on parents as essential partners in achieving academic and social success for students. A model that shows promise in initial research with children with behaviour difficulties is the Conjoint Behavioural Consultation model (CBC). Sheridan and Kratochwill (1992) defined CBC as “a structured, indirect form of service delivery, in which parents and teachers are joined to work together to address the academic, social, or behavioural needs of an individual for whom both parties bear some responsibility” (p. 122). Guided by the CBC model, parents and teachers share the responsibility for building a home-school relationship that will enhance the chances of a successful intervention program (Sheridan, Kratochwill, & Bergen, 1996). My intertwining to fit in model emphasizes the importance of models like the CBC model, for guiding consultation practice. With regard to training school psychologists as interventionists applying my model, Flanagan (2011) made a case for additional training of school psychologists in cognitive behavioural therapy to enhance their effectiveness in providing targeted intervention in brief meetings.

As indicated by parents in my study, specific knowledge of FASD is essential for professionals working with school-aged children with FASD. School psychology curricula should train students about the characteristics of children with FASD, how those
characteristics can affect school functioning, and the kinds of environmental interventions that can contribute to success for children. My model emphasizes the importance of simultaneously allowing caregivers to feel successful as parents while considering content about FASD. As pointed out by Paley and Olson (2009), it is critical that both school and mental health professionals are trained to recognize the continuum of effects associated with prenatal exposure to alcohol. My research findings emphasize that children affected by FASD are individuals that may differ in their displays of the effects of FASD.

6.4.3 Implications for Research

Because I paid careful attention to rigour throughout the research process, my substantive theory has the potential to guide further studies into caregivers’ perspectives. Most of the caregivers who participated in the study were connected to key workers or support groups, important conditions that helped them and their children stay intertwined to fit in. The stigma associated with FASD might have prevented those caregivers who were not connected to supports from participating in the study and may prove to be an ongoing barrier to recruiting these caregivers for other studies. Nonetheless, future research studies should focus on capturing perspectives of those caregivers managing their children’s schooling who are not connected to key workers or support groups. Studies with those caregivers can illuminate some barriers to accessing support for such caregivers.

Only two participants in the study were foster parents. Given that many children with FASD live with foster parents (Besinger, Garland, Litrownik, & Landsverk, 1999), it would be essential to include more foster parents in future research studies and explore issues around power differences and legal responsibility for the children. Foster parents in my study
indicated they felt like second class citizens who had to rely on external authorities for decisions about their children.

Findings from this study point to support groups as important contexts where caregivers can potentially learn the skills they need to orchestrate their children’s schooling. The support groups also offer opportunities for caregivers to reflect on themselves and redefine themselves as people who can stand firm (self-efficacious). Despite the increase in parenting support programs for caregivers of children with FASD, there is a lack of rigorous evaluation studies of their effectiveness, particularly their longer-term outcomes. Studies that undertake such evaluations are important to move the educational psychology field forward.

Caregivers of older children indicate that transitions from elementary to secondary schools are characterized by their anticipation of difficulties. They have concerns about their children’s learning and worry if they will be able to keep up with peers. For those caregivers in my study with older school-aged children, the looming transition from primary to secondary school intensified their anticipation of academic difficulties. Caregivers shared their apprehensions about obtaining adequate support, especially when their children made the transition to high school. Future research studies could target caregivers of older students who are undergoing transitional processes.

School district personnel may find it difficult to implement the kinds of supports needed to support school-aged children with FASD. School principals, for example, may find it difficult to assign teacher assistants due to restrictions that arise under collective agreements (New Brunswick Association for Community Living, 2004). Capturing the perspectives of school personnel of school-aged children with FASD will be important to illuminate barriers to creating necessary supports for children and their caregivers.
Finally, my review of the literature showed that caregivers of children with other invisible disabilities, such as ADHD, could share the same main concerns as caregivers of children with FASD. My intertwining to fit in model could be tested in research with caregivers of children with other invisible disabilities, such as ADHD.

6.5 Implications for Teachers/Principals/District Administrators

Teachers’ knowledge of FASD was an important condition that influenced the amount of time and energy caregivers spent intertwining to fit in. This finding is consistent with findings from Duquette and Stodel (2005) and Ryan and Ferguson (2006a, 2006b) that highlighted teachers’ knowledge of FASD as an important factor that affects the school experience of children with FASD. Recent research by Blackburn, Carpenter, and Egerton (2010) indicates that, although some teachers may have a moderate knowledge of FASD, specific strategies and interventions that can help students be more successful are less well understood. Specific training in the characteristics of FASD and strategies for classroom management of children with FASD, as outlined in special education resource documents (Province of British Columbia, 1996), is indicated; however, my research findings also highlight the important role of recognizing the individual needs of each student.

POPFASD (2011) introduced the Learner Environment Instruction Curriculum (LEIC) planning tool, intended to help teachers develop the IEP for students with FASD. The planning tool is designed to help teachers identify particular strengths and weaknesses of individual students and to make accommodations in the teaching environment and curriculum. Adopting a tool such as LEIC in BC schools is supported by the findings from the current study.
Certain conditions were important for caregivers’ efforts to reach desirable outcomes. The concept of communication-on-the-go; for example, was identified by caregivers as an important influence for reaching long-term outcomes. Communication-on-the-go is characterized by ongoing communication between caregivers and the school over longer periods of time. The informal nature of communication, in particular, where caregivers and teachers find ways to go beyond the usual structures that are typically used for communication between parents and school professionals (e.g., structured planned meetings) would be an important approach in schools.

Some caregivers commented on the importance of the role of the principal in affecting conditions in the classrooms. When principals understood the nature of FASD, there could be a positive trickle-down effect to the classrooms. Furthermore, when principals were flexible in the way they implemented supports in school and worked around systemic barriers to support children success for children and caregivers was more likely.

Caregivers identified turn-over in teaching staff as an important micro-system factor that influenced success for their children. They regarded union rules pertaining to the allocation of support people as failing to serve caregivers of children with FASD well. Because their children did not respond well to conditions of instability and change, caregivers were more likely to be called into the school and have to abandon their other sources of identity so they could be on call 24/7. The outcomes of potential effects on caregivers’ abilities to engage in financial employment have been discussed.

Caregivers’ perceptions of special education designation criteria as being ambiguous made advocating by “keeping at it” more difficult. The ambiguity is particularly difficult
when some care providers cannot connect their actions (e.g., persistent advocacy) with positive outcomes for their children (e.g., the allocation of an aide).

Finally, programs with open-door policies where parents are welcomed inside the school were also valued by parents. These considerations could be useful for teachers and principals attempting to construct school environments to support success of students with FASD.

6.6 Implications for Key Workers

Key Workers are “facilitators” whose mandate includes assisting caregivers and service providers of children with FASD to understand a child’s needs and to develop supportive environmental accommodations (Province of British Columbia, 2007). As described in policy documents, key workers interact with caregivers of children with confirmed or suspected FASD in a variety of ways, including providing emotional and practical support to families (Province of British Columbia, 2007). The findings in my study provide guidance (see Hume et al., 2008) about factors affecting the role of the key workers in supporting families with children with FASD in British Columbia.

My study findings indicated being connected to a key worker made intertwining to fit in easier for caregivers, provided that they perceived the relationship with their key worker as supportive and helpful. Participants defined a helpful relationship with a key worker as one where the key worker is knowledgeable about FASD, individualizes the support provided to the caregiver and their child (rather than “cutting and pasting” from a manual or generalizing from what worked for other caregivers), maintains a trusting relationship, and especially, is available immediately (or on a “9-1-1” basis) when help is needed. These elements provide
direction for key workers who are establishing relationships with children with FASD and their caregivers. Helpful relationships increase the likelihood that participants will “haul in” key workers to help with tactics to orchestrate schooling for their children intended to achieve successful outcomes. Sensitizing key workers to tactics parents are using can help them to support parents in their aims for their children. In particular, caregivers who do not view themselves as people who “stand firm,” find being connected to a helpful keyworker provides assistance with battling for support on their behalf at their child’s school. The findings enable keyworkers to appreciate what, for some parents, are viewed as supportive behaviours.

Many key workers also run parent support groups. Parent support groups are generally based on the premise that it is possible to change patterns of parent behaviour through explicitly teaching skills to identify and address children’s behaviours in new ways (Barlow, 1998). The findings provide direction to key workers to consider the importance of support groups for learning the skills from knowledgeable facilitators and other group members to advocate and educate effectively and for providing caregivers with occasions to reflect on themselves and redefine themselves as experts on their children. For keyworkers to create the kinds of support contexts that go beyond the dissemination of information, specific instruction to develop group facilitation skills could be important.

Finally, key workers can use my findings to increase benefits to caregivers by making support groups easily accessible, providing childcare, and developing a high level of trust between group members. Key workers can question caregivers about their perceptions of the kinds of supports offered to them and ways to assist them to access support groups. While
being connected to formal support is helpful, caregivers’ needs for informal and ongoing support are emphasized.

6.7 Significance of the Findings for Caregivers

Grounded theory aims are to produce interpretations that can explain social phenomena and also provide information of value to those engaged in the behaviour under study (Annells 1996; Glaser and Strauss 1967). When theory rings “true” and is relevant it has the potential to help individuals manage what they know with some control and understanding of the area of action (Glaser, 1978). Because my intertwining to fit in model conceptualizes and organizes many indicators under a few categories, it provides opportunities for caregivers to anticipate outcomes, conditions, and strategies, and reflect on the utility of the strategies and tactics they are using in relation to outcomes.

My findings clearly highlight the time-consuming nature of engaging in strategies to stay intertwined to fit in and their effects on caregivers. The emotional and financial costs to caregivers are clearly documented. While some caregivers have threats to physiological needs (i.e., adequate housing and access to medical care for their children and themselves) that require priority for those personnel supporting families, the caregivers’ need for belonging also drives their actions. My intertwining to fit in model emphasizes the importance of predicating supportive approaches on caregivers’ strong need to fit in and to be regarded as “good” parents. Caregiver groups could potentially advocate for these elements.

Olson et al. (2009), in their recent review of FASD and the family, emphasized the need for interventions geared towards caregivers of children with FASD to be focused on the
goal of increasing parents’ sense of self-efficacy. The findings from this study would support caregivers pursuing that direction.

Pearce and Gibbard (2011) emphasized that while empirical support has emerged for intensive attachment programs for infants and young children with attachment difficulties (see for example, Dozier et al., 2009), there is limited data regarding empirically supported and effective intervention treatments for attachment problems in school-aged children with FASD. Paley and O’Connor (2009) have pointed out that parenting strategies that are effective with other children may not work with children with FASD because of their difficulties with generalizing to new situations. They argued that enhancing the parent-child relationship may be a critical direction for interventional approaches with this population. The intertwining to fit in model highlights the importance of programs focused on parent-child attachment for caregivers of children with FASD.

The nature of FASD is such that caregivers need ongoing information to regulate their children’s behaviour. Being shunned by the school makes it more difficult for caregivers to have the kind of up-to-date information on their children they need to regulate the relationships with their children and reach outcomes of success for their children and themselves. From caregivers’ perspectives, it appears that schools would not be encouraging caregivers to connect outside the usual structures for communication when they have come to view the caregiver as a “problem parent” rather than an ally. Caregivers used language strategically to soften the advocacy message, some caregivers made use of the IEP process in a pro-active way, and others hauled in trusted support people to promote success. My model can be used to sensitize caregivers as to the kinds of tactics and conditions that could contribute to ongoing communication with the school.
My research findings indicate that the invisible nature of FASD led to all caregiver
types having to contend with blame when their children don’t fit in at school. This highlights
the importance of providing support to foster, adoptive and grandparents, in addition to
support for their children.

I intend to approach dissemination of my findings in ways that will ensure caregivers
benefit from the findings from my study. I have been invited to talk to caregivers at support
groups across the Lower Mainland, to key-workers supporting families with FASD, and will
also present at local and international conferences. I have offered to share a summary of my
findings with the families who participated in my study. I intend to prepare scholarly articles
to disseminate the findings to the scholarly community, to sensitize the educational system to
the main concerns of caregivers of school-aged children with FASD and how they work to
resolve these concerns, and to highlight potential lessons to educators and support personnel,
including key workers.

6.8 Summary

The purpose of this study was to explain how caregivers of school-aged children with
FASD manage their children’s schooling. I used a Glaserian approach to the grounded theory
method to develop a substantive theory, namely, intertwining to fit in. By identifying the
underlying pattern in what caregivers of school aged children with FASD do and say and
ordering this information into a system of interrelated hypotheses, I addressed unanswered
questions identified from the FASD and school psychology literature, including, what are the
main concerns of caregivers of school-aged children with FASD; how do they continuously
process these main concerns; what outcomes are they hoping to achieve; and how do
educational environments, educational policies, and factors such as stigma affect caregivers’ perceptions and behaviour?

The substantive theory adds to the FASD and school psychology literature in several significant ways. The theory explains that caregivers of school-aged children with FASD are continuously involved in a cycle where they attempt to stay in the relationship with their children and use a variety of strategies and tactics to move towards long-term outcomes such as success at school for their children and recognition as a parent and achieving a sense of self-actualization or accomplishment beyond the parental identity.

The theory highlights that caregivers directly responded to constantly shifting educational environments that detracted from their children’s success. My findings indicate that parents of school-aged children with FASD were more likely to regard the school system and its personnel as a threat to their children than as a support, except under the most favourable conditions. Moreover, societal expectations for social and emotional self-regulation in young children, a lack of knowledge about FASD, and the resulting unsupportive educational environments detracted from long-term success for parents. Caregivers identified useful programs where teachers and support staff are knowledgeable about FASD, where there is a lower student-teacher ratio, and where the environment is structured to reduce sensory triggers, accommodate students’ sensory needs, and have open door policies where parents are welcomed inside the school. In particular, ongoing and meaningful communication is a helpful condition. My findings also emphasize the complementary relationship between caregivers with FASD and their children and add to the extant literature by framing this relationship in terms of positive outcomes involving school-aged children and their parents.
My findings recast primary and secondary disabilities as micro-level influences that not only undermine children’s long-term outcomes of academic and social success but also the long-term outcomes for which their caregivers are striving. This is an important finding which supports calls for a focus on the prevention of secondary disabilities through early diagnosis, intervention, and supportive school environments.

Even under favourable conditions in schools, caregivers, including the single, unemployed, biological parents in my study, were instrumental in orchestrating success for their children. These findings counteract stigmatized versions of these parents found in the extant literature. The findings also indicate that caregivers regard paid employment and children’s success as mutually exclusive, which emphasizes the “double jeopardy” of parents of children with FASD living in poverty.

The implementation of provincial parent support and key worker programs emerged as important conditions that influenced caregivers’ efforts to stay intertwined with their children to fit in and reach their long-term outcomes of success. Caregivers in my study indicated that long-term relationships characterized by understanding of FASD and trust assisted them in employing the strategies and tactics they needed to intertwine to fit in. Conditions of ongoing, accessible and knowledgeable support, characterized by trust and respect were critical not only to children’s success, but also the success of their parents. All but one participant living in a setting that had been portrayed over the long-term as a community of people living in poverty and experiencing marginalization indicated that characteristics of their neighbourhood contributed to them intertwining to fit in. They described their community as “close-knit,” trusting, accepting and stable, and with continuous relationships over time. Caregivers also referred to the accessibility of support
and services for both them and their children and the flexible criteria that made it easier for them to access the kinds of supports that helped them stay intertwined to fit in. These findings are significant because they contrast with information about this community, which typically emphasizes homelessness, unemployment, addiction, crime, and mental illness.

In this chapter, I referred to the research product of this thesis as the “intertwining to fit in” model. In the first section, I compared the substantive theory with the extant literature. I focused my discussion on four main conceptualizations: intertwining to fit in; keeping up appearances; orchestrating schooling; and the conditions that influence intertwining to fit in, in particular, conditions of support. I then discussed the limitations of the study, with a focus on constraints around the developmental nature of grounded theory, the study sample, and the data collection strategy of participant observation. I followed this with a discussion of the implications of the study, including those for school psychology practice, education, and research. I also detailed implications for teachers and keyworkers. I concluded this chapter with the significance of the findings for caregivers.
References


Clark, E., Hughes, K. & Jaswal, O. (2010, November). *So you have the assessment, now what about the teacher?* Paper presented at the meeting of the British Columbia Association of School Psychologists, Vancouver, BC.


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Appendices

Appendix A: Advertisement

Are you the primary caregiver of an elementary school aged child with Fetal Alcohol Spectrum Disorder (FASD)?

Seeking: Primary caregivers (biological parents, long-term fosterparents, adoptive parents, and other long-term adult caregivers) of elementary school aged children (ages 5-12) with FASD.

For: Research project that is examining how primary caregivers manage their child’s schooling. We want to talk about how caregivers manage their child’s schooling. 4.5 to 5 hours over the course of 4 months at a place of your convenience

Remuneration: $25.00 and cost of childcare and travel if applicable

Principal Investigator: Laurie Ford, Ph.D.
Department of Educational & Counselling Psychology & Special Education; University of British Columbia

Co-Investigator: William McKee, Ph.D.
Department of Educational & Counselling Psychology & Special Education; University of British Columbia

If you are interested in taking part or learning more contact:

Suretha Swart, Ph.D. Candidate & Co-Investigator
Department of Educational & Counselling Psychology & Special Education
University of British Columbia
Tel: xxxxxxxxxx
Email: xxxxxxxx
Appendix B: Information Letter

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational & Counselling Psychology, & Special Education
2125 Main Mall
Vancouver, B.C. Canada V6T 2B5

MANAGING THEIR CHILDREN’S SCHOOLING: PERSPECTIVES OF CAREGIVERS OF ELEMENTARY SCHOOL AGED CHILDREN WITH FASD

Parent/Caregiver Information Letter

Principal Investigator: Laurie Ford, Ph.D.; Associate Professor
Department of Educational & Counselling Psychology & Special Education
Phone: xxxxxxxxxxx Email: xxxxxxxxxxx

Co-Investigators: Suretha Swart, M.A.; Ph.D. Candidate
Department of Educational & Counselling Psychology & Special Education
Phone: xxxxxxxxxxx Email: xxxxxxxxxxx

William McKee, Ph.D. Assistant Professor
Department of Educational & Counselling Psychology & Special Education
Phone: xxxxxxxxxxx Email: xxxxxxxxxxx

Date: January 5, 2009

My name is Suretha Swart and I am a doctoral student in School Psychology at the University of British Columbia. I am doing a study to find out how caregivers of children (ages 6-12) manage their children’s schooling. To do this, I would like to talk to caregivers/parents like you.

I am writing you to see if you would be willing to talk to me about your experiences with your child’s schooling. If you agree to take part in the study or need to know more, please contact me at xxxxxxxxxx. We can talk on the phone and then plan a time to talk more at a time and place of your choice if you want to take part.
If you take part in the study I will ask you to talk to me about your experiences in trying to manage your child’s schooling. There will likely be two or three interviews that will last for about one hour each. This means that we would talk for about 4.5 to 5 hours over the 4-month period if you take part in the study. To help me to remember what we talked about, I will audiotape the interviews. A typist or myself will type the audiotapes. The typist will sign an agreement to not share the information with anyone. I will also take notes before the interview and directly after to remind me of what I have seen. You will have a chance to discuss any questions you may have regarding the study prior to the first interview. If you have any notes, emails, letters or other documents about your experiences that you want to share with me to help me understand how you manage your child’s schooling that would be helpful as well but not required. All the information (audiotapes, electronic and paper copies) will be stored in a locked filing cabinet in my home during the study and will be stored in a locked cabinet at UBC when the study is completed. Your name, your child’s name and other identifying information will not appear on the transcripts. Code numbers will be used instead of names. Your name will not be used in the final write up, at talks about the research, or in possible publications.

I hope that the findings from my study will be helpful to caregivers of children with FASD and help teachers and others understand the experiences of caregivers of children with FASD. In addition I hope the findings will contribute to further research into ways to better support children with FASD and their caregivers/parents in schools.

You will receive $25.00 for taking part in the study. I will also reimburse you for any travel costs (e.g. bus fare, parking fare) if you travel to the interview. I will also refund you for childcare that you may need during the time you talk with me up to a maximum of $15.00 per hour.

I hope to hear from you and that you will have interest in working with me on this project. If you have any questions, please do contact me at xxxxxxxxxx or by email at xxxxxxxxxx.

Regards,

Suretha Swart
Appendix C: Consent Forms

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational & Counselling Psychology, & Special Education
2125 Main Mall
Vancouver, B.C. Canada V6T 2B5

MANAGING THEIR CHILDREN’S SCHOOLING: PERSPECTIVES OF CAREGIVERS OF ELEMENTARY SCHOOL AGED CHILDREN WITH FASD

Parent/Caregiver Interview Consent

______________________________
Principal Investigator: Laurie Ford, Ph.D.; Associate Professor
Department of Educational & Counselling Psychology & Special Education
Phone: xxxxxxxxxxxx Email: xxxxxxxxxxxxxxxx

______________________________
Co-Investigators: Suretha Swart, M.A.; Ph.D. Candidate
Department of Educational & Counselling Psychology & Special Education
Phone: xxxxxxxxxxxx Email: xxxxxxxxxxxxxxxx

William McKee, Ph.D. Assistant Professor
Department of Educational & Counselling Psychology & Special Education
Phone: xxxxxxxxxxxx Email: xxxxxxxxxxxxxxxx

Date: January 31, 2009

______________________________
Dear Parent or Caregiver,
Please read the following form carefully. Sign one copy and return to the researcher during the initial interview. Keep the other copy for your records.
This is a request for you to take part in our study. You are being asked to take part in this study because you are a parent or caregiver of an elementary age child with FASD.

**Purpose:**
The purpose of this study is to learn how you manage your child’s schooling. Learning from parents/caregivers is a very important step in creating educational environments where children with FASD and their caregivers are supported.

**Research Study Participation:**

1. Taking part in this study means that you agree to:
   a. Take part in an initial one-to-one interview that will take about 60 minutes to 90 minutes of your time.
   b. Take part in 2-3 follow up interviews that will take about 45-60 minutes of your time.
   c. Observations and notes made about the meeting to be included in the study write up.
   d. Consider the sharing of documents such as e-mails, letters, notes or reports that may help the researcher to understand how you manage your child’s schooling. This may not be applicable in all cases, and is up to you to decide to share these documents.

   The total time approximately 4.5 to 5 hours over approximately 4 months

2. The one-to-one interviews will be audio-taped for later transcription. The person doing the transcription will sign an agreement that they will not share the information.

3. After each meeting you will have a chance to review the transcript of our earlier interview(s).

4. Your taking part is voluntary and will not affect any services that your family or child receives. You have the right to withdraw from the study at any time and you have the right to not answer any of the questions.

5. This research will be used in part for the doctoral dissertation of Ms. Swart.
6. All information you share during the interviews is confidential. Only the investigators of the study will see your responses. All documents have a code number only with no names on the transcripts or write-ups. The documents will be kept in a locked filing cabinet. No one will be identified by name in any reports of the completed study.

7. You will receive general information about the results of this study when the study is done.

8. The cost of transport to attend meetings away from your home, if any, will be covered by the researcher. The cost of childcare to take part in the study will be covered by the researcher up to a maximum of $15.00 per hour.

9. You will receive $25.00 to thank you for taking part in the study.

10. The information you provide may help to enhance understanding amongst teachers and other service providers of what it is like to manage FASD on a day to day basis.

11. While not anticipated, there is always the chance that talking about your child’s FASD and your attempts to manage this may be upsetting. We are providing a list of names and contact numbers of professionals that can support you should you like to receive further support.

12. If at any time you have concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at xxxxxxxxxxx.

If you have any questions or concerns about the project you may contact either Dr. Ford or Ms Swart at the numbers listed above.

THANK YOU FOR TAKING PART IN OUR STUDY
MANAGING ELEMENTARY SCHOOL AGED CHILDREN’S FASD IN THE CONTEXT OF SCHOOL AND RELATED SYSTEMS:
CAREGIVER PERSPECTIVES

Parent/Caregiver Consent Form

Please check one of the following:

_______ Yes, I agree to take part in this study.

_______ No, I do not wish to take part in this part of the project.

If you agree to take part in this study:

Participant’s signature (please sign): ______________________________________

Participant’s name (please print your name): ________________________________

Date: ___________________________________________________________________

Your signature indicates your agreement to take part in the study and that you have received a copy of this consent form (Pages 1-3) for your own records.
Appendix D: Intake Form

Inclusion Criteria Checklist for Initial Screening

The following criteria will be reviewed with participants who contact the researcher to express an interest in participating in the study. If they meet the criteria and express an interest in taking part after discussing the study on the phone with the investigator, a copy of the consent form will be sent and a meeting time and location will be set. Note one checklist will be completed for each potential participant.

Date of Phone Screening: ________________________________

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you the <strong>primary caregiver</strong> of a child who was exposed prenatally to alcohol?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Primary caregiver for the purposes of this study means-</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>biological parents, long-term foster parents, adoptive parents,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and other long-term adult caregivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the child in your care <strong>prenatally exposed to alcohol</strong> to best of your knowledge?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has this child been in your care for at least one year?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the child in your care elementary age?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is English a primary language or a language in which you have conversational proficiency (can take part in interviews without the use of a translator)?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Yes, the participant meets the inclusion criteria

Yes, the participant is interested in taking part in the study

If yes, name and contact information of the participant

If yes, check to indicate a consent form and an information letter has been sent in advance of the initial meeting

If yes, date, time, and location of initial meeting:

Date: ________________________________

Time: ________________________________

Location: ________________________________
Appendix E: Initial Interview Guide

INITIAL INTERVIEW GUIDE

An initial interview will be scheduled with all eligible participants interested in taking part in the study. An overview of the study will be provided and the consent form will be reviewed and consent obtained before moving forward with the study. Once the participant has agreed and questions have been answered the initial interview will begin. General background information will be gathered using the background information form. Participants will be given the choice of completing this on their own in writing or by interview.

As this is a grounded theory study an initial interview will be conducted. Once the interview is completed, analyzed and reviewed, initial follow up interviews for more detail and clarification may be scheduled (up to 3 additional interviews beyond the initial intake).

The following general question will start the interview:

How do you manage … (child’s name) schooling? I would like for you to take some time to reflect upon these experiences and tell me about it. Feel free to talk about whatever comes to mind:

Note: Follow up questions will be asked depending on the response by the participants. Potential follow up questions include:

Additional questions for first interview:

1. Does FASD affect your child’s schooling and if so how?

2. How do you engage with your child’s school? Has this changed over time? How has this changed over time?

3. What factors affects and influences how you manage your child’s schooling? Does the school environment affect how you manage your child’s schooling and if so how?
4. Has managing your child’s schooling changed over time? How has managing your child’s schooling changed over time?

5. Does your child receive any supports inside of school? What are the kinds of supports your child receives? How did it happen that your child received these supports?

6. What things have been helpful to you as a parent?

7. What kinds of things have been difficult to you as a parent?

8. What could you tell other caregivers of school–aged children with FASD?

9. Are there any questions I should have asked? Do you have any questions for me?
Appendix F: Observation Guide

MANAGING THEIR CHILDREN’S SCHOOLING: PERSPECTIVES OF
CAREGIVERS OF ELEMENTARY SCHOOL AGED CHILDREN WITH FASD

Observation Guidelines

The following observations will be made at the time of the interview. The researcher will write notes on these observations.

1. Initial Impressions:

2. Description of the Interview Environment:
   
a. Location:
   
b. Physical Description of the Environment:
      
i. Room Configuration:
      
ii. Other People Present (e.g., children in background):
      
iii. Physical Objects in Room (e.g. coffee cup):

3. Description of Participant:
   
a. Physical Descriptors:
   
b. Clothing:
   
c. Non-Verbal Behaviour (Actions) Before and After Interview:
   
d. Verbal Behaviour:
      
i. Voice: Tone, Volume, Rate of Speech
   
e. Affect (e.g. facial expressions, crying):

4. Overall Impressions of Interaction:
Appendix G: Confidentiality Statement

MANAGING THEIR CHILDREN’S SCHOOLING: PERSPECTIVES OF CAREGIVERS OF ELEMENTARY SCHOOL AGED CHILDREN WITH FASD

Confidentiality Agreement

I understand that the information given to me to transcribe are data from a research investigation.

I agree to keep confidential all information pertaining to this investigation, including the identities of the research participants involved in the project as well as any references the participants make to their own children or others in their lives.

I agree to only discuss the research project with the Investigators of this project.

I agree that while I do the transcription, I will only refer to the research participants and all other individuals by initial, pseudonym, or ID number in order to maintain confidentiality.

I will not include participants’ names on any transcribed data.

I have read and understand these expectations for my work as a transcriptionist on this project.

________________________________________
Signature of the Transcriptionist

________________________________________
Printed Name of the Transcriptionist

________________________________________
Date
Appendix H: Example of Visual Representations
Appendix I: Example of Fieldnotes

Participant #5 Thursday, April 9, 2009

Single mother, lives with daughter

I arrived early to participants’ house. Boxes and mattress outside-mentioned she was moving. Received phone call. Participant is running late. Mentioned she had an appointment with her MLA-to talk about “how can we teach the teachers.” Concerned about running late to pick up daughter. Mentioned that daughter (10) has “never been away” from her-mom’s “always there.” Concerned about dogs and cats-do I mind having them around? House close to school-can see the school from the front drive-way. Introduced me to her friend who is also the caregiver of a child with FASD. Bumper sticker on van: “Proud offspring of dysfunctional parents”

I interview caregiver in kitchen. Brochures from summer programs, very organized portable storage bin with folders (info on FASD resources, assessment reports), lots of papers with information about summer programs, doctors’ visits, name of MLA on paper. Also newspaper clipping with article about her daughter and her quest for finding services. Quote in frame against wall: “Don’t judge what you don’t understand.”

Initial Impressions: I received an e-mail prior to our interview. E-mail from participant signed off with quote: “may you be content with yourself just the way you are” Participant asked many questions about process and research. She also e-mailed to remind me of the upcoming long weekend and how that will affect the interview-she seems very organized.
Very busy, multi-tasking all the time, making sure I feel at home, keep the dog and cat away, look at cellphone, watch time, concerned about pick-up time, call friend for daughter’s pick-up. Speaks with big voice, firm handshake, very expressive. Cry easily.

I walked with her to school gate-explained it is long weekend-students are very excited. Special days affects her daughter. Daughter late-difficulty with wanting to sweep the floor. Principal intervened. Participant mentions if it wasn’t for principal-he changed-increased knowledge of FASD.

Impressions: Riding a roller coaster: up and down, trying to “escape” the cycle, difficulties at school affecting ability to work, keeping at it even when things go well, financial constraints means having to do things yourself, need to be close at all times (purposeful move to a house very close to school), comments about school system seems different than participants from DTE (knowledge of FASD); actions is about wanting child to know you care; concerned about how she presents.
Appendix J: Example of Initial Memo

A Memo about the main concern (February 24, 2009)

What are the main concerns of the caregivers? I am asking myself, “What is this a study of?”

“What is going on?”

From interview 1: “Keeping child on-track” AND “Keeping themselves on-track.

Caregivers are working hard to keep things on-track. They work hard to keep their children on-track, AND ALSO, keep themselves on-track. Being off-track has consequences for child and self. Trying to get (closer to?) on-track and going off-track is an ongoing cycle. Tracks for parent and child seem connected. From interview 2 Staying on track Keeping everyone on schedule is important. Having to be on-schedule and organized not to loose track. If one gets affected (sick), everything is off track. If parent is not prepared, child goes off-track.

Like dominoes, if one falls , all fall.

If the parent “falls off”, the child “falls-off”. If the child falls off, the parent has to work harder to stay on. [Image of 2 people on a windsurfer, trying to balance on both sides; if one pushes to much, the other one goes down and vice versa] . A constant process of falling off and getting back “on”. Constant vigilance (a full-time job) to try and keep things on-track. It is about hard work and being prepared. Why do they work so hard, what keeps them going? I want to understand “on-track” better. What do they work hard for? What is “on-track?” From 1.1 line 19 “a comfort zone” (for my child) ; A comfort zone (for myself). Yes, but what does this look like?. What does a comfort zone look like?
O.k, she rejects the FASD label/FAS diagnosis label. What is this about? This is about not wanting her child to stand out. A place where they don’t stand out. (Fit in) What is the main concern: Not wanting her child to stand out. Does “not wanting child to stand out” create a comfort zone for caregiver? Does it? Is it connected? Not sure yet.


What does parent want (goal?): Also about turning things around

Main concerns:

(For child): Finding a place where they can fit in; finding support for child in school; breaking the cycle

(For self): Finding support for self; feeling less alone ; feeling good/not bad about parenting
Appendix K: Memo Detailing Development of the Core Category

Sept 1, 2010. Managing schooling represents as a repeating, circular and convoluted journey. This process is much like a roller coaster ride with many ups-and downs. The circle repeats often or every year; every year is different. Four stages emerged: Anticipating, Actively Managing, Hitting Rock Bottom and “Circling Up/Resolving”. Circling up is not resolving, they are never resolving, just trying to process or trying to resolve. Circling up is more like re-connecting. Conditions emerged for each stage. Parents are pulled between tensions. (The tensions I was trying to get at has to do with their regulation of intertwining)

I have revisited my description of the core category as a “process” in memos dating September 30-October 3, 2011. Not process but a cycle. Glaser’s (2005) description of the theoretical code, “cycling,” seemed to fit the pattern that was captured by the core variable. According to Glaser, cycling refers to repeatedly going over the same path or different paths in succession, and to actions or interactions that spiral downward and upward. O.K. so the cycle of intertwining to fit in captures the pattern of behaviour that explains how caregivers of elementary school-aged children with FASD continuously try to resolve their main concerns: preventing their children from failing academically and in social interactions, and, preventing themselves from being regarded as “bad” parents. The core category as a cycle was captured early on (e.g., April 13, 2009, p. 9; August 30, 2010: circle; visual of an ongoing roller coaster ride, September 1, 2010, p. 10, 16; Sept 1, 2010, p. 2; Sept 1, 2010 visual model ). The core category as a cycle is clear. I have cycle documented throughout and across.
It appears that one of the dimensions is the constant regulating of the amount of intertwining. The amount of intertwining is the relationship with their children. This is like attachment theory—the attachment system that gets activated in times of danger. But caregivers move closer and further to also present as good or avoid being viewed as bad. There is a constant moving closer and moving away. The movement towards and away is influenced by what is happening at school, child factors/caregivers and conditions. This is due to changing conditions (See memos Sept 1, 2010 pg 39-40). I referred to this dimension in earlier memos where I explored constant managing of dynamic tensions. Through regulating the relationship (the amount of intertwining), they avoid becoming too distant, or, on the other hand, so close that they can’t fit in and their children can’t fit in. I captured the constant observing and vigilance for change, so they can know how to direct their energy and time to stay intertwined. If caregivers are too intertwined neither they nor their children can sustain the level of involvement necessary to fit in; however, if caregivers and their children are less intertwined, sometimes to the point where their relationships become distant and are threatened with loss, neither they nor their children can fit in. Regulating the amount of intertwining involves managing dynamic tensions between being too involved or too distant. Purposeful actions of moving closer, moving away This is needed so they can stay intertwined to fit in. I captured this “dimension” in earlier memos [See memo, entitled, “Need to know” following Interview 3. March 23, 2009, p. 4; memo 2010-09-22 “staying connected while circling out”; Also memos September 1, 2010 pg. 29-30].
Appendix L: Developing Theory (Early Stage of Integration)
Appendix M: Demographic Information

MANAGING THEIR CHILDREN'S SCHOOLING: PERSPECTIVES OF CAREGIVERS OF ELEMENTARY SCHOOL AGED CHILDREN WITH FASD

Participant Background Information

The following background information will be gathered as a part of the initial intake meeting. It will be conducted in an interview format. However the participants will be given the opportunity to complete in writing on their own if they prefer:

Date: ____________________________  Participant #: ____________________________

Your Age: ____________________________

Your Sex: _______ Male _________ Female

Relationship with the Child (check one):

_____ Biological Mother  _____ Biological Father

_____ Long-term Foster Mother  _____ Long-term Foster Father

_____ Adoptive Mother  _____ Adoptive Father

_____ Other Female Caregiver (please specify): __________________________________

_____ Other Male Caregiver (please specify): ________________________________

What is your highest level of education?

_____ Less than Grade 8

_____ Less than High School Diploma

_____ High School Diploma

_____ Some college, trade school, university

_____ Diploma/Certificate college/trade school

_____ Baccalaureate Degree

_____ Post Baccalaureate Diploma or graduate degree

What is your current employment status?

_____ Working Full-Time Outside of the Home

_____ Working Part-Time Outside of the Home

_____ Full-Time Student

_____ Part-time Student

_____ Not Employed Outside the Home
What best describes your ethnicity (check one)
   _____ White/Caucasian
   _____ Aboriginal
   _____ Asian/Pacific Islander
   _____ South Asian
   _____ Other, please specify________________________________________

How many years have you been parenting this child? *********

Age of your child? ********

Number of years the child has been in school (including Kindergarten)? ********

Child’s current grade in school? ********

Does this child receive services as a child with Special Needs in the school?
   _____ Yes    _____ No

Has this child received a formal medical diagnosis of FAS?
   _____ Yes    _____ No

Please note any other comments you wish to make:
Appendix N: Memos (Later Stage of Integration)

September 30-October 3, 2011 (Process Memo)

I have the main concerns: success for children in the school system and being regarded as a ‘good parent’.

I have a core variable, Intertwining: To Fit In (the core variable explains how caregivers continuously process or try to resolve the main concerns). It explains what is going on for caregivers of school-aged children with FASD (not attended to in the existing literature) and explains their behaviour, which is my rationale for doing the study. What is going on for them and why do they behave the way they do? Glaser writes about why substantive grounded theory is important in Theoretical Sensitivity (chpt 1). Conceptualizing what is going on and explaining why they behave the way they do will have practice implications (for those who work with them in schools) and implications for caregivers. Glaser writes on how substantive theory can benefit the participants themselves.

Wanting to fit in is about using strategies to increase the likelihood that will happen. The strategies are an attempt to move “the fitting in agenda” forward.

I have two main strategies that increase the likelihood that fitting in would happen, Orchestrating Schooling and Keeping up Appearances, each with 4 properties, or 4 related tactics. These 2 main strategies are intertwined in that outcomes from one affects the other.

Orchestrating Schooling: being on stand-by; pitbullling; cultivating connections; anticipating difficulties

Keeping up Appearances: sharing information, reframing relationships, resisting structures, redefining self

I have a third “category”, with related properties, namely Regulating the Relationship. This goes on all the time in the background while they are Orchestrating Schooling and Keeping Up Appearances. I am thinking that Regulating the Relationship is another strategy, with related tactics. Regulating the relationship is about staying intertwined with their children so they can use the fitting in strategies. They need to stay intertwined because the children can’t fit in without the parents and the parents won’t fit in unless the children are successful. In my model I can represent Regulating the Relationship as a straight line going through the intertwined helix.

Regulating the Relationship: shifting expectations; contemplating forever; *third property

Note: *I don’t know what to call this third property. I want to capture the “persistent state of vigilance” they are in to be able to regulate the relationship-gauging was used by a participant “using her kid as a gauge to determine what to do next.” They are constantly
monitoring and putting themselves in a position to see what is going on, e.g., volunteering at the school. These parents cannot rely on their kids to tell them what is going on and information is not always forthcoming from the school-to stay intertwined they are forced to gather information.; another part of regulating the relationship is constantly adjusting their actions based on the information they obtain by putting themselves in a position to monitor their kids.

OUTCOMES of the two main strategies are: Hitting Rock Bottom and Reaching Islands of Calm. I call it outcomes now because HRB and IOC mostly result from actions of caregivers in interaction with conditions. HRB happened when strategies are unsuccessful and IOC happened when strategies are successful. Caregiver actions also affect the conditions. Conditions change constantly and affect the strategies. These 2 categories represent critical junctures. It is clear that all participants experience HRB and Islands of Calm at different points over time, but Rock Bottom and Islands of Calm looks slightly different for different participants. For example, different levels of exhaustion, more guilt for biological caregivers, shorter duration for those in close-knit community, exacerbation of feelings under conditions of lack of support(Although all participants experience HRB and IOC, I no longer call it stages? See below where I consider calling it stages).

HRB presented in the visual model looks like the strands of the helix pulled apart. Not completely apart because in the case of the mother whose child was removed she was still referred to by the school and concerned about keeping up appearances, so rather than completely untwined, less closely intertwined. When they are in rock bottom, they are no longer closely intertwined to fit, and question whether they will remain intertwined. They don’t engage in strategies to move the fitting in agenda forward but perhaps are still regulating the relationship.

Outcomes of HRB is: being shunned, excluding yourself, exhaustion, grief, guilt, loosing faith in the system, increased negative feelings about themselves (not good and responsible). When caregivers are in RB, their children’s school placements are jeopardized or they face loss of placement.

O.K., now we are in Rock Bottom. There are 2 types of strategies associated with HRB: Dealing with HRB (while they are in HRB) and Moving out of HRB (and back towards closely intertwined so they can move the fitting in agenda forward.). I wonder if having strategies to deal with HRB is correct-when you are in HRB, doesn’t that exclude taking action? However, Glaser would argue that even doing nothing (as , for example, in “waiting it out”) is a strategy. So perhaps referring to the category Dealing with HRB as a strategy, will work. Dealing with HRB has related properties, or tactics. I wonder if I can call it Surviving RB ?There is another strategy associated with HRB, namely, Moving out of HRB back towards Orchestrating Schooling and Keeping Up Appearances. Getting out of HRB happens to everyone and is important because they always wants to get back to intertwining to fit in to attend to their main concerns. Moving back to rock bottom makes it easier or more difficult depending on conditions (e.g., availability of supports) So in a visual model it is
going from being loosely intertwined/untwined to being more intertwined again, so they can move their agenda forward.

Dealing with RB: Waiting it out; taking time out; distancing self; disengaging

Moving out of HRB: Changing Settings; repositioning self; connecting

Alternative scenario

Oct 5: New note: I am again looking at feedback and perhaps Dealing with HRB should disappear and I should collapse Dealing with HRB and Moving out of HRB and call it Moving out of HRB. Then the tactics associated with Dealing with HRB (e.g. waiting it out) can become tactics for Moving out of HRB.

So the category will be named Moving out of Rock Bottom. The tactics will be: waiting it out, repositioning self, changing setting to fit in, taking time out, connecting.

Distancing self and disengaging are collapsed into outcomes, rather than tactics to deal with RB.

If I collapse these I would have: Moving out of HRB: Changing Settings; repositioning self; connecting; waiting it out; taking time out

There are also Islands of Calm. Islands of calm are reached by all from time to time and mostly as an outcome of caregiver actions (yes, definitely) and sometimes due to chance (e.g., the caregiver whose child had a teacher one year with children of FASD of her own). On my visual model this is a closely intertwined section of the helix

Outcomes of Islands of Calm: happiness, respite “good parent”. When caregivers are in islands of calm, some success for their children socially and academically

There are strategies associated with Islands of Calm. I call these Capitalizing on Islands of Calm, with tactics: throttling down strategies, delegating stand by and attending to self.

All of these are affected by Conditions. Conditions affect strategies, outcomes, and the 2 pivotal points/critical junctures. Because conditions constantly change (also as a result of caregiver actions), caregivers constantly move between orchestrating schooling/keeping up appearances and HRB and IOS

When conditions change, islands of calm gets “jeopardized”-the closely intertwined helix becomes less closely intertwined. Because being closely intertwined is important in order to move the fitting in agenda forward/important so they can process their main concerns, they need to get back to orchestrating schooling/keeping up appearances. To get from Islands of Calm back to engaging in strategies to fit in, they engage in the strategy of keeping at it through advocating and educating. When islands of success are jeopardized through changing
conditions, they need to “dial up” the strategies, particularly they engage in advocating and educating through keeping at it.

The main components of my theory are:

1. The core variable: Intertwining: To Fit In

   The strategies, with related tactics/properties: Note to self: If social organization of life is always about solving the relevant problems as Glaser stated, the strategies need to be about the core variable and how that works to solve the main concerns, So:

2. The strategies Orchestrating Schooling, Keeping Up Appearances, Regulating the Relationship, Getting out of Rock Bottom and Moving from Islands of Calm back to Orchestrating Schooling/Keeping Up Appearances are all about Intertwining to fit in The strategy Capitalizing on Islands of Calm is more about fitting in beyond fitting in as a parent. The strategy Dealing with Rock Bottom is not about pushing the fitting in agenda forward so much, but it is about surviving/dealing with rock bottom (s not completely “unraveling”/untwining), so that so you can eventually move back to intertwining for fitting in.

3. The critical junctures: HRB and Islands of Calm (critical junctures are outcomes of the main 2 strategies: Orchestrating Schooling and Keeping UP Appearances)

4. There are Outcomes related to each of the 2 Critical Junctures

5. Conditions that affect strategies, critical junctures and outcomes

<table>
<thead>
<tr>
<th>Orchestrating Schooling</th>
<th>Keeping Up Appearances</th>
<th>Regulating the Relationship</th>
<th>Dealing with Rock Bottom</th>
<th>Capitalizing on Islands of Calm</th>
<th>Getting out of Rock Bottom</th>
<th>Moving from Islands of Calm to Orchestrating Schooling and Keeping Up Appearances</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being on standby</td>
<td>Sharing Information</td>
<td>Shifting Expectations</td>
<td>Waiting It Out</td>
<td>Dealing Down Strategies</td>
<td>Changing Settings</td>
<td>Keeping Up Through Advocating and Educating</td>
</tr>
<tr>
<td>Pitching</td>
<td>Reframing Relationships</td>
<td>C-Contemplating Forever</td>
<td>Distanting Self</td>
<td>Delegating Stand-by</td>
<td>Repositioning Self</td>
<td></td>
</tr>
<tr>
<td>Anticipating Difficulties</td>
<td>Resisting Structures</td>
<td>? Gaining</td>
<td>Disengaging</td>
<td>Attending to Self</td>
<td>Connecting</td>
<td></td>
</tr>
<tr>
<td>Cultivating Connections</td>
<td>Redefining Self</td>
<td>? Taking Time Out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HOWEVER

Alternative scenario: Now that I have said the core variable is no longer a BSSP, because I no longer have stages, I am not sure about that. Before I saw Actively Managing as a stage (with orchestrating schooling and keeping up appearances), HRB as a stage and Islands of Calm as a stage. I am unsure if stages should disappear from the theory, because I think some criteria of stages are met in my theory:

1. I have a sense of change over time
2. Consequences of one stage may be a second stage (Glaser, 1978, p. 98). So consequences of orchestrating schooling and keeping up appearances, namely, HRB and IOC, may signal a new stage.
3. I do have strategies and conditions affecting each stage and I have consequences/outcomes for HRB and IOC
4. I have a sense of temporal limits/time dimension. For example, institutional timing e.g. the start of a new school year brings upon a new stage of Orchestrating Schooling/Keeping Up appearances

If I am going to see Actively Managing, Islands of Calm, Hitting Rock Bottom as 3 stages, then what about “Fitting In beyond Fitting in as a parent”. This is captured by attending to self in my description above, however, Fitting In Beyond Fitting in as a Parent can be a new stage, except it only happens when Islands of Calm last long enough that parents can attend to self. I don’t think all parents in my study experienced calm long enough to get to this “stage.”

October 21, 2011

I am moving regulating the relationship into intertwining for fitting in. RTR is not a separate strategy, but rather part of how they are intertwining to fit in. A dimension of intertwining to fit in

Dec, 2011

I need to look at how I word my main concerns. The caregivers are trying to process a problem. Caregivers are trying to process the problem of avoiding failure for their children and themselves. Success is the outcome. Eight categories: two main strategies, orchestrating schooling and keeping up appearances, with their related tactics and sub-tactics; conditions that influenced the throttling up or throttling down of strategies and tactics; two critical junctures, hitting rock bottom and islands of calm; outcomes associated with the critical junctures; the strategy, re-engaging, with its associated tactics; and overall/long-term outcomes associated with the core category.
Appendix O: Caregiver and Child Characteristics

Table O-1 represents the caregiver’s characteristics. Caregivers are identified by the order in which they were recruited, gender, age, caregiver type, and ethnicity. I include their relationship status, highest level of education, and employment status. Children are identified by age, followed by grade and gender.

Table O-1: Caregiver and Child Characteristics

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Relationship Status</th>
<th>Highest level of Education</th>
<th>Employment Status</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (F) (35) Biological mother Aboriginal</td>
<td>Single</td>
<td>Less than high school diploma</td>
<td>Part-time</td>
<td>9 (4) (F)</td>
</tr>
<tr>
<td>2 (F) (39) Biological mother Fillipina</td>
<td>Single</td>
<td>Some college, trade school, university</td>
<td>Student</td>
<td>11(6) (F)</td>
</tr>
<tr>
<td>3 (F) (58) Grandmother Aboriginal</td>
<td>Single</td>
<td>Less than grade 8</td>
<td>Not Employed</td>
<td>8 (4) (F)</td>
</tr>
<tr>
<td>4 (F) (49) Adoptive mother Caucasian</td>
<td>Single</td>
<td>Some college, trade school, university</td>
<td>Part-time</td>
<td>6 (1) (M)</td>
</tr>
<tr>
<td>5 (F) (44) Biological mother Caucasian</td>
<td>Single</td>
<td>Some college, trade school, university</td>
<td>Not Employed</td>
<td>9 (4) (F)</td>
</tr>
<tr>
<td>6 (F) (61) Grandmother Aboriginal</td>
<td>Single</td>
<td>Some college, trade school, university</td>
<td>Not Employed</td>
<td>11 (6) (M)</td>
</tr>
<tr>
<td>7 (F) (50) Adoptive mother Caucasian</td>
<td>Married/Common Law</td>
<td>College diploma</td>
<td>Part-time</td>
<td>9 (5) (M)</td>
</tr>
<tr>
<td>8 (F) (44) Adoptive mother Caucasian</td>
<td>Married/Common Law</td>
<td>Graduate degree</td>
<td>Full-time</td>
<td>6 (1) (M)</td>
</tr>
<tr>
<td>9 (F) (47) Foster mother Caucasian</td>
<td>Married/Common Law</td>
<td>Baccalaureate degree</td>
<td>Student</td>
<td>11 (6) (M)</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Relationship Status</td>
<td>Highest level of Education</td>
<td>Employment Status</td>
<td>Child</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------------</td>
<td>-------------------------------------</td>
<td>-------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>10 (F) (29) Biological mother</td>
<td>Single</td>
<td>High school diploma</td>
<td>Student</td>
<td>11 (6) (M)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 (F) (50) Adoptive mother</td>
<td>Married/Common Law</td>
<td>Some college, trade school,</td>
<td>Not Employed</td>
<td>12 (6) (F)</td>
</tr>
<tr>
<td>Caucasian</td>
<td></td>
<td>university</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 (F) (36) Stepmother</td>
<td>Married/Common Law</td>
<td>Less than grade 8</td>
<td>Part-time employed</td>
<td>11 (6) (M)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td></td>
<td>(grade 7)</td>
<td>Maternity leave</td>
<td></td>
</tr>
<tr>
<td>13 (F) 28 Biological mother</td>
<td>Single</td>
<td>Less than high school diploma</td>
<td>Not Employed</td>
<td>7 (2) (M)</td>
</tr>
<tr>
<td>Caucasian</td>
<td></td>
<td>(grade 11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 (M) 52 Biological father</td>
<td>Single</td>
<td>Less than high school diploma</td>
<td>Not Employed</td>
<td>12 (7) (M)</td>
</tr>
<tr>
<td>Caucasian</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 (F) 35 Biological mother</td>
<td>Single</td>
<td>Less than high school diploma</td>
<td>Part-time employed</td>
<td>6 (1) (M)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td></td>
<td>(grade 10)</td>
<td></td>
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</tr>
<tr>
<td>16 (F) 52 Foster mother</td>
<td>Single</td>
<td>Some college, trade school,</td>
<td>Part-time</td>
<td>8 (4) (F)</td>
</tr>
<tr>
<td>Caucasian</td>
<td></td>
<td>university</td>
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<tr>
<td>17 (F) 54 Adoptive mother</td>
<td>Married/Common Law</td>
<td>Graduate degree</td>
<td>Not Employed</td>
<td>11(6) (M)</td>
</tr>
<tr>
<td>Caucasian</td>
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